Home-Based Chemotherapy for Cancer

Issues for Patients, Caregivers and the Health Care System

AGENCE D'ÉVALUATION DES TECHNOLOGIES
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Issues for Patients, Caregivers and the Health Care System

Report prepared for AETMIS
by Lucy Boothroyd and Pascale Lehoux

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Scientific review
Alicia Framarin, M.D. (gyneco-obstetrics), M.Sc. (health administration), Scientific advisor

Proofreading
Suzie Toutant

Communications and dissemination
Richard Lavoie, MA (communications)

Co-ordination and page layout
Jocelyne Guillot

Collaboration
Lise-Ann Davignon, M. Sc. (community health)

For further information about this publication or any other AETMIS activity, please contact:

Agence d'évaluation des technologies et des modes d'intervention en santé
2021, Union avenue, suite 1040
Montréal (Québec) H3A 2S9

Telephone: (514) 873-2563
Fax: (514) 873-1369
E-mail: aetmis@aetmis.gouv.qc.ca
Web site: www.aetmis.gouv.qc.ca

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The mission of the *Agence d'évaluation des technologies et des modes d'intervention en santé* (AETMIS) is to contribute to improving the Québec health-care system and to participate in the implementation of the Québec government's scientific policy. To accomplish this, the Agency advises and supports the Minister of Health and Social Services as well as the decision-makers in the health care system, in matters concerning the assessment of health services and technologies. The Agency makes recommendations based on scientific reports assessing the introduction, diffusion and use of health technologies, including technical aids for disabled persons, as well as the modes of providing and organizing services. The assessments take into account many factors, such as efficacy, safety and efficiency, as well as ethical, social, organizational and economic implications.

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Jean-Marie R. Lance
Economist, Senior Scientific Advisor

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Dr. Réginald Nadeau
Cardiologist, Hôpital du Sacré-Cœur, Montréal

Guy Rocher
Sociologist, Professor, Département de sociologie, and Researcher, Centre de recherche en droit public, Université de Montréal, Montréal

Lee Soderstrom
Economist, Professor, Department of Economics, McGill University, Montréal

FOREWORD

HOME-BASED CHEMOTHERAPY FOR CANCER: ISSUES FOR PATIENTS, CAREGIVERS, AND THE HEALTH CARE SYSTEM

Home care is the fastest growing service delivery model in industrialized nations, and raises a number of significant issues and implications for health care decision-makers in Québec. Advances in cancer treatment modalities and technological improvements have made it possible to offer some forms of chemotherapy safely in the home under strict conditions.

The current assessment is part of a series of reports initiated by AETMIS on the use of health technologies in the home setting. The report is particularly timely given current cancer care initiatives by the *Programme québécois de lutte contre le cancer*.

In this report, the term 'home chemotherapy' denotes any modality of administration of chemotherapeutic agents for cancer cure or control at home (intravenous, subcutaneous, oral, etc.), with or without on-site supervision by a nurse. This assessment reviews the evidence concerning effectiveness, safety, patient preference and satisfaction, patient quality of life, and costs of home chemotherapy. Organizational, access, and patient choice issues were also examined. Published information was enriched with interviews with home chemotherapy providers at selected institutions in Québec and, for comparison, in Ontario, a province with similar demographics but a markedly different organizational structure for cancer care.

Establishing safe chemotherapy practices at home is resource intensive and requires a well-integrated, collaborative team of health care professionals. The home delivery model cannot wholly replace outpatient nor inpatient treatment, but can be a safe and acceptable option for some cancer patients who choose it, particularly those receiving continuous infusion therapies. The report recommends standardization of home treatment programs, enhanced collaboration between health care providers, and a comprehensive model of provincial cancer services that ensures the patient's continuity of care. However, due to insufficient evidence on effectiveness, the perspective of cancer patients in Québec and particularly cost implications in comparison with outpatient settings, there is a need for well-designed evaluations of home chemotherapy before its use is greatly expanded in Québec.

In submitting this report, AETMIS wishes to provide the best possible information on this mode of treatment delivery to decision-makers in Québec's health care system.

Renaldo N. Battista
President

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QUÉBEC

Sylvie Bélanger, R.N., M.Sc., Oncology Nurse Clinician, Oncology Department, *Hôpital Maisonneuve-Rosemont (Centre affilié à l'Université de Montréal)*, Montréal

Jacynthe Brodeur, R.N., *Chef d'unité, Centres d'oncologie CHUM, Hôpital Notre-Dame*, Montréal

Carol Burnett, R.N., Head Nurse Hematology/Oncology/BMT, **Kim Winnicki**, R.N., Outpatient Department, and **Brigitte Pépin**, R.N., Day Hospital—Hematology/Oncology, at the Royal Victoria Hospital, Montréal

Joyce Constantin, R.N., Nurse Manager, and **Diane Lamarre**, R.N., Assistant Nurse Manager, Inpatient Unit 17-East, Montréal General Hospital, Montréal

Hélène Croteau, Head Nurse, Hemato-oncology clinic, *Centre hospitalier universitaire de Québec – Hôtel-Dieu de Québec*, Quebec City

Antoinette Ehrler, R.N., Head Nurse, Oncology Department, and the Outpatient Oncology Nursing Team, Sir-Mortimer B. Davis—Jewish General Hospital, Montréal

Guylaine Filion, R.N., Oncology Nurse, Oncology Outpatient Department, *Centre Hospitalier des Vallées de l'Outaouais*, Gatineau

Suzanne Frenette, B.Pharm., M.Sc., Pharmacist, Oncology Department, *Hôpital Maisonneuve-Rosemont (Centre affilié à l'Université de Montréal)*, Montréal

Nicole Ladouceur, R.N., Oncology Department, *Hôpital Maisonneuve-Rosemont (Centre affilié à l'Université de Montréal)*, Montréal

Danielle Ménard, R.N., M.Sc., Nurse Coordinator, Oncology Department, *Cité de la Santé de Laval*, Laval

Arnaud Samson, M.D., Vice-President, *Conseil québécois de lutte contre le cancer* (until June 30, 2004), *ministère de la Santé et des Services sociaux*, Quebec City and Baie-Comeau

Johanne Soucy, R.N., Incharge Nurse, Oncology Day Treatment Centre, Montréal Children's Hospital, Montréal

ONTARIO

William Evans, M.D., Executive Vice-President, Clinical Programs, Cancer Care Ontario, Toronto

Deborah Gravelle, R.N., Chemotherapy Home Infusion Pump Program (CHIPP) Coordinator and Charge Nurse, Ottawa Regional Cancer Centre, Ottawa

Kathryn Hughes, Nursing Manager, Northwest Ontario Regional Cancer Centre, Thunder Bay

Kevin Imrie, M.D., Medical Director, Medical Oncology, Toronto-Sunnybrook Regional Cancer Centre, Toronto

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Brigitte Boilard, Pharmacist, *Centre Hospitalier Universitaire de Sherbrooke*, Fleurimont, QC

William Evans, M.D., Executive Vice-President, Clinical Programs, Cancer Care Ontario, Toronto, ON

Deborah Gravelle, R.N., Chemotherapy Home Infusion Pump Program (CHIPP) Coordinator and Charge Nurse, Ottawa Regional Cancer Centre, Ottawa, ON

Visal Uon, B.Pharm., M.Sc., Chief, Pharmacy Department, *Hôpital Charles LeMoyne*, Greenfield Park, QC

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SUMMARY

A recent AETMIS report on high-tech home care—of which home-based chemotherapy for cancer is an example—found home care to be the fastest growing service delivery model in industrialized nations, and raised a number of significant issues and implications for health care decision-makers in Québec [Lehoux and Law, in press]. Recent advances in cancer treatment modalities and technological improvements have made it possible to offer some forms of chemotherapy in the home under strict conditions, related to the specific protocol prescribed, caregiver availability, motivation, and training, the home environment and location, and patient characteristics.

In this report we use the term 'home chemotherapy' to denote any modality of administration of chemotherapeutic agents at home (intravenous, subcutaneous, oral, etc.), with or without on-site supervision by a nurse. Examples thus include short-term infusions by a nurse (staying in the home throughout delivery), multi-day continuous infusions started by a nurse at a hospital and continued (without on-site supervision) at home, and injections delivered by parents in the home to a child. It should be noted that oral therapies in particular are not always considered by the medical community as home chemotherapy *per se*; in some places, 'home chemotherapy' is used more strictly to refer to treatment which is entirely carried out by a nurse in the home. We use the broad definition in order to capture the reality of current home-based cancer treatment in Québec and to be more inclusive in the scientific literature.

Cancer is responsible for almost 30% of the total annual deaths in Québec. It was estimated that there would be 35,500 cases diagnosed in Québec in 2003, the most frequent being breast cancer for women (expected incidence=110/100,000) and lung cancer for men (101/100,000) [NCIC, 2003]. The probability of ever having cancer has increased to 43% among men and 37% among women in Québec [MSSS, 1997b]. Hospitalization costs alone related to cancer amounted to $317 million in 1994-95 [MSSS, 1997a, 1998], and social and health costs (direct and indirect) in 1993 totalled about $3 billion in the province [MSSS, 1997b, 1998]. Total direct and indirect costs related to cancer in Canada in 1998 were estimated at $14.2 billion [Health Canada, 2002].

The Québec *ministère de la Santé et des Services sociaux* (MSSS) established a *Programme de lutte contre le cancer*, a *Conseil québécois de lutte contre le cancer* (CQLC)*, and a *Centre de coordination de la lutte contre le cancer au Québec* (CCLCQ)* in order to improve the quality and organization of services in cancer care in the province [MSSS, 1997b, 2001]. Our report is particularly timely given these current cancer care initiatives, which address organizational frameworks at the local, regional and provincial level, continuity of care, access to high quality oncology services, and patient quality of life, among other issues. We searched the scientific literature and reviewed the evidence concerning effectiveness, safety, patient preference and satisfaction, patient quality of life, and costs of home chemotherapy for cancer. We also examined organizational, access, and patient choice issues. This comprehensive review was supplemented with semi-structured interviews with service providers at selected institutions in Québec (n=10) and, for comparison, in Ontario (n=6), a province with similar demographics but a markedly different organizational structure for cancer care. The goal of the interviews was not to carry out a complete survey of programs but rather to collect perspectives on the benefits, barriers, facilitating factors, and challenges in providing home chemotherapy.

We utilized a broad approach to address the issues surrounding home chemotherapy for patients, their caregivers—both professional care providers and informal helpers such as family members—and the Québec health care system in general. In response to the needs of rural patients, for whom home chemotherapy is unlikely

* On July 1, 2004, the CQLC and the CCLCQ will be merged into the *Direction de lutte contre le cancer* (DLCC), which was created on April 1, 2004, as part of the administrative framework of Québec's ministère de la Santé et des Services sociaux (MSSS).

to be available or possible, we also examined a second treatment delivery model: 'closer to home' chemotherapy delivered at local clinics or hospitals and managed by general practitioners.

OVERVIEW OF HOME CHEMOTHERAPY FOR CANCER

In this report, we focus on chemotherapy in adults for cancer control and cure, rather than end-of-life cancer care. Chemotherapy involves the administration of cytotoxic drugs that prevent the growth and proliferation of cells, and is especially used in cancer treatment in order to destroy neoplastic cells that show uncontrolled growth. For some cancers chemotherapy may be the only treatment offering cure (e.g. Hodgkin's disease, acute myelogenous leukemia), while for breast and colon cancer, chemotherapy can often cure if combined with surgery/radiation. In other cases, chemotherapy has controlling effects and can extend life without signs of disease for many years (e.g. chronic lympocytic leukemia). In advanced or metastasized cancers, chemotherapy has been shown to alleviate symptoms and can extend survival. The specific treatment plan (e.g. drugs prescribed, delivery regimen, length of therapy) depends on the kind of cancer, its location, the degree of cancer spread, the effect of the disease on body functioning, the patient's general health status, the body's response to the chemotherapy, and the therapeutic goals. Cancer chemotherapy can be administered in many different ways, including orally, intramuscularly, and subcutaneously; the most common method is intravenously. Chemotherapy is usually delivered in treatment cycles, with non-treatment "rest" periods (of several days or weeks) in between; prolonged treatments are also increasingly used (e.g. 24 hours to 6 weeks of continuous drug infusion), which may increase efficacy and/or decrease drug toxicity, depending on the specific treatment protocol. For intravenous push, intravenous short infusion, or injection regimens, home chemotherapy (if permissible) usually replaces outpatient treatment; for intravenous continuous infusions of 24 hours in duration or longer, home treatment replaces inpatient hospitalization.

Due to the toxicity of the drugs, chemotherapy delivered in any setting is usually associated with a number of distressing side effects for the patient (e.g. nausea, vomiting, hair loss, fatigue). For intravenous treatment at home, there is the additional risk of complications related to the need for technical skills and the nature of the devices and agents used. The premise behind home therapy is that cancer patients may prefer to receive their treatments at home, if it is possible to do so, rather than at a hospital (as inpatients or in an outpatient department). The approach can be appealing to the patient for a number of reasons including receiving therapy in the comfort and security of the home, decreased travel to medical facilities, reduced risk of nosocomial infection, an increased sense of control over treatment and illness, and less disruption of family life.

EVIDENCE FROM THE LITERATURE ON BENEFIT, COSTS, AND SAFETY

There is insufficient evidence on the clinical effectiveness of home chemotherapy compared to non-home settings (for outcomes such as survival, remission rates, or tumour control). There is more evidence to show that home treatment can be delivered safely, with few serious complications or accidents, although patients must be carefully selected and trained. Where home chemotherapy replaces inpatient treatment, convincing evidence of cost savings for hospitals and families arises from only one pediatric study. In studies where home chemotherapy replaces outpatient treatment, the mixed findings and variable study quality prevent a conclusion on the cost implications. Home chemotherapy causes cost shifting within the health care system from hospitals to home care organizations. Effects on costs to Québec hospitals and home care services, and to cancer patients and their families/informal caregivers, require more study. Improvements in patient quality of life at home have not been well documented in the literature, but are consistently reported anecdotally by care providers. Patient preference for and satisfaction with home therapy is supported, although the published evidence in this regard mostly arises

from studies where acceptance of the approach is required to participate.

INFORMATION FROM PROVIDERS ON CURRENT HOME CHEMOTHERAPY SERVICES

In our interviews with service providers in Québec (n=10; two in rural regions) we looked at the availability of home chemotherapy, patient eligibility criteria, role of hospital staff, cost issues, role of CLSCs, patient satisfaction, rural Québec treatment settings, organizational barriers and challenges, and facilitating factors. The components of different home treatment programs varied with respect to a number of factors, including structure, use of specific program guidelines, emergency procedures, and staff. Home visits by an oncology nurse were not provided by any of the programs. Use of CLSC services was highly variable. Oncology nurses and pharmacists had a pivotal role in managing the home therapy. Only one urban site had a specific budget for home chemotherapy. Interviews with rural providers pointed to a greater need for alternative outpatient delivery of chemotherapy 'closer to home' in remote areas (at local hospitals), rather than home treatment. Barriers to providing home chemotherapy services included limited resources, a requirement for high levels of nurse commitment, training, and autonomy, lack of organized collaboration with CLSCs, and a lack of program and protocol standardization.

Based on our interviews with service providers in Ontario (n=7 at six sites; one rural) it appears that the structure and financing of cancer and home care services in Ontario contributes to a capacity for greater patient load, greater uniformity of services, and inter-organizational collaboration that is more fully supported and developed. Access to chemotherapy both at home and 'closer to home' is facilitated in Ontario by centralized funding, a regionalized approach, support of alternative outpatient delivery (fostering liaisons between cancer centres and community hospitals), involvement of general practitioners in a network of rural chemotherapy clinics, access to oncology expertise through communication links, and certification of community chemotherapy clinics. Home nursing visits during treatment (with on-site supervision throughout drug delivery for subcutaneous injections only) were an integral part of the home chemotherapy program at three of the four urban Ontario hospitals we studied. Organizational issues highlighted by contacts from both provinces related to the need for collaboration with community-based services, the importance of initiative and support by a multidisciplinary team, the role of nurses and pharmacists in program management, patient education, and home support, the need for sufficient outpatient resources, and the importance of communication and training links between different team members involved in home and 'closer to home' treatment.

ORGANIZATIONAL, ETHICAL, AND LEGAL ISSUES

The delivery of home chemotherapy requires high quality, integrated services by a specially trained multidisciplinary team in partnership with motivated, trained patients and their caregivers. This is particularly important for intravenous treatment, but is also relevant for oral treatment and other delivery modalities at home. Intra-organizational issues include the need for specialized nursing training and responsibilities, adherence to care and safety policies, education and transfer of skills from nurses and pharmacists to patients and informal caregivers, and coordination of services. A key aspect of home chemotherapy services is the requirement for a team of health professionals from various disciplines to work together. If communication networks are not strong, there is a real likelihood of fragmentation of care. Without team collaboration, the quality standards achieved for chemotherapy in the hospital setting will not be present in a home treatment service. A need for formalization of team functions and responsibilities emerged as another theme in our interviews. Coordination of chemotherapy services, particularly as treatment moves from the hospital to the community and home setting, is crucial. This coordination, in turn, is related to the overall organizational model for provincial cancer care. Of utmost importance is the ability of the service team to respond to the cancer patient's needs. A

truly comprehensive cancer care system is one that provides supportive services (e.g. access to counselling and home help) and commits the necessary human and financial resources to ensure a continuum of care from the hospital to the community setting.

Home chemotherapy presents legal and ethical challenges related to the home setting (where a nurse may visit alone, and/or the patient under treatment may be unsupervised), the potential for side effects and even life-threatening events due to the toxicity of the drugs, and the specific context of being diagnosed with cancer. The most important aspect of home chemotherapy delivery, when applicable and available, is acceptance of the treatment by the patient. Assisting with the administration of chemotherapy and management of the equipment requires both patients and their informal caregivers to gain highly technical skills. The patient with cancer must be fully informed about the implications of chemotherapy protocols in general and receiving therapy at home in particular. The professionals in the multidisciplinary home chemotherapy team must follow policies that reflect best practices. The person(s) ultimately responsible for the patient's care at home must be clearly identified. There are highly restrictive patient eligibility criteria for home chemotherapy, in order to minimize risks to safety. For some cancer patients, there will be no choice but to receive treatment in an institutional setting: patients in rural settings have less access to chemotherapy at home. For patients in rural areas, the 'closer to home' chemotherapy model (treatment delivery at rural hospitals managed by general practitioners) provides them with more choices and helps lessen their travel burden.

CONCLUSIONS AND RECOMMENDATIONS

Establishing safe chemotherapy practices at home is resource intensive and requires a well-integrated, collaborative team of health care professionals. Chemotherapy in any setting requires specially trained personnel. Evidence is insufficient on effectiveness, cost implications, and the patient's perspective, particularly in comparison with outpatient settings. The home delivery model cannot wholly replace outpatient treatment, especially in the rural setting, but can be a safe and acceptable option for some cancer patients who choose it, particularly those receiving simple continuous infusion therapies. Certain conditions must be in place in order to ensure high quality chemotherapy in the home setting; these aspects should be taken into account when such initiatives are implemented. We make several recommendations about these conditions below. This assessment has led us to an additional recommendation related to access to chemotherapy: for rural cancer patients in Québec, priority needs to be given to the establishment of 'closer to home' chemotherapy. We have grouped our recommendations for Québec policy-makers, health care administrators, and care providers according to a number of issues:

(1) Support for program evaluation

In light of the insufficient evidence, there is a need for well-designed evaluations of home chemotherapy before its use is greatly expanded in Québec. In our interviews, we noted a lack of funds and time availability to carry out program evaluation, although one Québec site we visited had received a clinical innovation prize for their program initiative, for which an evaluation report had been completed. Comprehensive and ongoing evaluation of home chemotherapy programs is a crucial aspect of quality control. Program developers should be rewarded for their initiative and achievement of certain standards of care. Eligibility for specific home treatment funding from regional authorities could be linked to program evaluations which show appropriate positive outcomes. Program assessments must include the patient's perspectives on quality of life and satisfaction; patients and informal caregivers take on many care responsibilities during home chemotherapy. Economic evaluations of programs should apply a societal perspective, including costs of drugs, medical supplies and equipment, personnel (including time spent on patient teaching and follow-up, telephone contact with patients, and home visits), hospital service use (at outpatient clinics, emergency rooms, and inpatient departments), community health service use (at CLSC clinics), drug storage and delivery, teaching manual and

program development, other supportive care use (e.g. domestic help, counselling), and expenses saved/lost by the patient and his/her family and caregivers (e.g. travel, child care, employment income).

We view the evaluation of existing home chemotherapy programs in Québec as a priority in the light of insufficient data on effectiveness, costs, and the patient's perspective. In the meantime, the following issues should be considered by both program evaluators and current providers.

(2) Standardization of general policies and program components

Considering the current provision of home chemotherapy in Québec, we observed a need for basic provincial policies that set safety and program standards and provide structure for chemotherapy services both at home and in the rural hospital clinic environment. Several of our contacts stressed the importance of current initiatives to standardize treatment protocols. This could be extended to centralized policies specifying the basic components of both home chemotherapy programs and 'closer to home' services (with respect to organizational structure, staffing requirements, professional training, communication links, emergency patient support, and patient follow-up, for example). Initiatives such as the extensive chemotherapy guide developed by the *Regroupement des pharmaciens en oncologie* should be supported and widely diffused, and are an important step towards standardization of policies. In Ontario, greater uniformity of services and capacity to respond to both urban and rural patients' treatment needs appeared to be assisted by a regionalized approach with centralized funding, inter-organizational collaboration, and a certification system for rural clinics using standardized protocols.

(3) Enhanced collaboration and communication

The formation of multidisciplinary teams working together to provide the best care to the patient undergoing home or 'closer to home' chemotherapy is essential. This can be facilitated through standardized patient information sheets, the designation of a key health professional to coordinate care for the cancer patient, and training programs (e.g. oncology nurse—CLSC nurse teaching; teleconferencing and other remote communications for rural health professionals, site visits, annual conferences). At some sites, it could be useful to form a coordination team to liaise between the different organizations involved (e.g. hospitals and CLSCs).

(4) Central standard setting but a regionalized approach

At the same time as detecting a need for standardized policies to ensure quality of care in home chemotherapy programs, we recognized the diversity of initiatives at different institutions and in different regions (e.g. rural versus urban). Central surveillance of programs, as a component of cancer treatment services, could be managed by a body such as the MSSS or DLCC. Roles for such an organization could include setting basic standards and general objectives. However, the specific planning and budgeting for programs should likely fall under the domain of the *Agences de développement de réseaux locaux de services de santé et de services sociaux* (formerly the *régies régionales*), who are better able to respond to the needs of their specific areas. A strategy could be developed whereby multidisciplinary hospital teams are encouraged to submit proposals to the *agences* regarding a home chemotherapy or 'closer to home' treatment service, in order to receive funding for program delivery and evaluation. In this way, regional bodies would be able to ensure high quality services while allowing for flexibility since different institutions (e.g. hospitals, CLSCs) may differ in their enthusiasm to be involved in these program initiatives. For example, depending on the site, oncology nurses could be involved in making home visits, or CLSC nurses could have more involvement in cancer care and be able to obtain specialized training. A regionalized approach is, in fact, favoured by the *Programme de lutte contre le cancer* and the DLCC initiatives.

(5) Increase in resources and use of specific budgets

The home chemotherapy programs we examined in Québec were restricted by a lack of financial and human resources (nurses, pharmacists), despite there being a general consensus that demand for services at home would increase. De-

pending on the results of proposed program evaluation, increased resources will likely be needed by existing home chemotherapy initiatives in Québec, and particularly if services are expanded, in order to guarantee high quality of care. The financial support of the transfer of skills from oncology to community nursing appears to be lacking. Sharing of expertise is crucial for continuity of care. The use of specific budgets for home chemotherapy relieves the burden of having to 'borrow' nursing time from inpatient and outpatient departments. Although only a minority of chemotherapy patients are able to have treatment at home at present, the technological and safety aspects are such that an integrated approach involving a number of different health care professionals must be sufficiently resourced. The value of supportive care services in the community—for cancer patients receiving chemotherapy both at outpatient clinics and at home—cannot be under-estimated.

(6) A comprehensive model of provincial cancer care

Finally, in carrying out this assessment it became apparent that issues regarding chemotherapy access and giving cancer patients the choice of quality treatment in the home environment are fundamentally related to the overall vision of and policies for cancer care in the province. A home chemotherapy program, in fact, presents a 'microcosm' of the general issues in cancer care: the need for comprehensive services that address different patient needs at different stages of their illness/treatment process and the integration of many disciplines and services to promote wellness. The objectives delineated by the *Programme de lutte contre le cancer* and the CCLCQ's (now integrated to the new *Direction de lutte contre le cancer*) initiatives in cancer care organization represent an important starting point for the development of a comprehensive framework that addresses the varied and changing needs of cancer patients in Québec.

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1 INTRODUCTION AND BACKGROUND

In this report we use the term 'home chemotherapy' to denote any type of administration of chemotherapeutic agents at home (intravenous, subcutaneous, oral, etc.), with or without on-site supervision by a nurse. Examples thus include short-term infusions by a nurse (staying in the home throughout delivery), multi-day continuous infusions started by a nurse at a hospital and continued (without on-site supervision) at home, and injections delivered by parents in the home to a child with cancer. It should be noted that oral therapies in particular are not always considered by the medical community as home chemotherapy; in some places, 'home chemotherapy' is used more strictly to refer to treatment which is entirely carried out by a nurse in the home. We use the broad definition in order to capture the reality of current home-based cancer treatment in Québec and to be more inclusive in the scientific literature.

This report examines the issues surrounding home chemotherapy for cancer in order to make health policy recommendations for Québec. After placing this assessment in context, we present an overview of cancer chemotherapy in general and home chemotherapy in particular in section 1. Section 2 describes the study objectives and methods used in our evaluation. In section 3, we look at the evidence in the scientific literature concerning the clinical benefit, costs, safety, and patient impact of home cancer chemotherapy. Based on qualitative interviews with service providers and administrators, section 4 looks at home chemotherapy activity in Québec and presents information from Ontario for comparison. This section also introduces the concept of 'closer to home' chemotherapy as a treatment delivery model. Section 5 builds on issues highlighted in sections 3 and 4 by examining organizational, ethical, and legal implications of home chemotherapy for Québec, and discusses alternative settings for outpatient chemotherapy delivery. The report closes in section 6 with conclusions and recommendations.

1.1 POLICY CONTEXT

1.1.1 Need for this assessment

A recent AETMIS report on high-tech home care—of which home chemotherapy for cancer is an example—found home care to be the fastest growing service delivery model in industrialized nations, and raised a number of significant issues and implications for health care decision-makers in Québec [Lehoux and Law, in press]. A survey of Québec CLSCs *(centres locaux de services communautaires)*, conducted by Lehoux and colleagues in 1999-2001, showed that 35.6% have been involved in the delivery of intravenous chemotherapy (on site and at home) [Lehoux and Law, in press]. Chemotherapy has been part of the movement to leave the hospital setting as protocols have moved administration out of in-hospital wards to outpatient departments and then, in some cases, to the home. There is growing evidence that home chemotherapy can be a safe option favoured by cancer patients under certain conditions; there has been, however, conflicting evidence on cost-effectiveness (e.g. decreases in hospital stay versus costs in outpatient clinics versus increases in home nursing) and limited research on clinical effectiveness, treatment compliance, and patient quality of life. Due to the toxicity of the drugs used, there are many safety and technical issues involved in the administration of home chemotherapy for cancer.

In 2001, we conducted an orientation meeting with nursing staff at an urban university teaching hospital, where a nurse-initiated home chemotherapy pilot project (for continuous infusions) had delivered care to 12 Québec cancer patients in the last year. Among other issues, these contacts highlighted lack of resources, lack of collaboration between hospitals and CLSCs, lack of designated regional cancer treatment centres, and a need for extensive patient/caregiver training as important concerns for this service. Despite

positive patient response, the funding and organizational restrictions faced by this project meant that home visits could not be provided: patients still returned to the hospital for a check-up every 72 hours and used hospital—not community—services if problems arose (outside office hours, only emergency room consultation was possible).

Cancer is the leading cause of premature death in Canada, accounting for about one-third of potential years of life lost [NCIC, 2003]. Cancer is responsible for almost 30% of the total annual deaths in Québec [MSSS, 1994]. Québec data show that 29,900 new cases of cancer were diagnosed in 1996 [NCIC, 2001]. It was estimated that there would be 35,500 cases diagnosed in Québec in 2003, the most frequent being breast cancer for women (expected incidence of 110/100,000) and lung cancer for men (101/100,000) [NCIC, 2003]. The probability of ever having cancer has increased to 43% among men and 37% among women in Québec; in the last 10 years, the number of persons that have died from cancer has risen by 31% [MSSS, 1997b]. Hospitalization costs alone related to cancer amounted to $317 million in 1994-95 [MSSS, 1997a], and social and health costs (direct and indirect) in 1993 totalled about $3 billion [MSSS, 1997b]. Total direct and indirect costs related to cancer in Canada in 1998 were estimated at $14.2 billion [Health Canada, 2002]. The physical and psychological suffering experienced by cancer patients can be extensive; however, with current treatment modalities such as chemotherapy many cases can be successfully cured.

The Québec *ministère de la Santé et des Services sociaux* has established a *Programme québécois de lutte contre le cancer* and a *Direction de lutte contre le cancer* (DLCC), who takes over the mandate of the *Conseil québécois de lutte contre le cancer* (CQLC, a consulting body with a knowledge transfer mandate) and the *Centre de coordination de lutte contre le cancer au Québec* (CCLCQ) in order to improve the quality and organization of services in cancer care in the province (www.msss.gouv.qc.ca) [MSSS, 2001]. This program relies on collaboration between the 18 *agences régionales*, the DLCC, the *Institut de santé publique*, and the ministry. The development of this program was informed by almost four years of work by the *Comité consultatif sur le cancer*, which involved about 150 care providers [MSSS, 1997b]. Group discussions and a qualitative study were carried out on the needs of cancer patients [Fraser, 1995]. Among other responsibilities, the DLCC will examine cancer care organization in the province and will coordinate the efforts of all bodies involved [MSSS, 2001]. Each regional agency has been asked to form a committee *(Comité régional de lutte contre le cancer)*, made up of care providers, cancer patients, and the general public, to develop a plan that addresses their most pressing needs. The regional agencies are responsible for adapting and implementing their own programs on the basis of the orientations proposed in the provincial strategy.

Goals of the *Programme québécois de lutte contre le cancer* included:

- re-organize prevention activities and services offered to oncology patients and their families, in order to respond to rising demand, increase the effectiveness of the fight against cancer, and improve the connection between patient needs and services;
- establish an integrated network and form interdisciplinary oncology teams at the local, regional, and supra-regional level, to improve communication and sharing of expertise between diverse cancer care providers and to permit patient access to services throughout the province;
- use CQLC (composed of cancer care providers, researchers, and administrators) to advise the ministry on (1) issues related to patient needs, access to services, and service organization; (2) quality assurance criteria; (3) evolution of medical practices in accordance with scientific and clinical progress; and (4) methods of evaluating interventions and the organization of the integrated network;
- increase the 'humanization' of cancer care through such measures as a key care provider and resource person who coordinates services for the patient and his/her family and provides follow-up for the duration of the patient's

illness, and services that take psychological and social needs into account;

- create a standardized information file for each cancer patient, which can be used by specialists and family physicians to monitor treatment received locally and regionally;
- determine the level of access to oncology services and expertise across the province and re-think strategies to improve access to most services closer to home, as part of a local and/or regional plan;
- improve service links by formalizing reference networks to supraregional services in such a way that patient follow-up can be made more systematic and services at different levels can be respected;
- assure a continuum of services at health care institutions and at home, in order to respect patient choice and maintain quality of life at the highest level possible.

The key theme of the program is *Pour lutter efficacement contre le cancer, formons équipe* ("to strengthen the fight against cancer, build teams"). A network of multidisciplinary teams at different levels is viewed to be central to improving access to high quality services and exchange of expertise. At the local level, such teams would be responsible for the support and follow-up of patients and for service delivery (particularly chemotherapy, supportive measures, and end-of-life care). Regional teams would serve as expertise 'reference points' for local teams with respect to tumour sites or type of service (e.g. palliative care), and could have a decisional role for more specialized treatments. Finally, supraregional teams would serve as consultants to the other teams and would be involved in treatment decisions and delivery for complex cases, such as those requiring experimental or intensive chemotherapy protocols. A further objective is for each regional agency to have an 'interdisciplinary intervention team' to integrate its health promotion and cancer prevention activities.

There thus appears to be a significant need to examine the issues surrounding home cancer chemotherapy for patients, caregivers, and the health care system in Québec. Our report is particularly timely given current cancer care initiatives in the province, which address access to chemotherapy treatment closer to home, organizational frameworks at the local, regional and provincial level, continuity of care, and patient quality of life.

1.1.2 Potential impact of home chemotherapy and this report on the health care system

This care delivery model—and our assessment of it—have potential impact at the following three levels in the health care system (according to levels presented by Battista and collaborators [Battista et al., 1999]):

- at the *macro* level: as part of policy decisions concerning what combination of hospital, clinic, and community-delivered care best serves the Québec population with cancer and their families;
- at the *meso* level: for decision-makers in Québec hospitals and CLSCs, regarding the role of such service providers in cancer treatment, the costs of service delivery, and the level of collaboration required between these two bodies;
- at the *micro* level: for nurses, physicians, pharmacists, and other service providers working with this patient population (and their families), concerning the most effective, feasible, and appropriate care delivery models.

1.1.3 Potential stakeholders in the health care system

The potential stakeholders who could be affected by this report and action stemming from it include (a) Québec patients with cancer and their families and informal caregivers; (b) physicians, pharmacists, other service providers, and particularly nurses (who are the most involved in actually delivering the treatment, and have a

pivotal role in managing home chemotherapy programs); (c) decision-makers and administrators at the CLSC and hospital level; (d) decision-makers and administrators at the regional health boards; (e) policy-makers at the provincial health and government levels. There are potential roles for other stakeholders, outside the health care system, since the organization of home care services also relates to community and social services in general and could thus be of concern to providers and decision-makers in this milieu. We have attempted to consider the perspectives of each of these potential stakeholders in our assessment.

1.2 DEFINITION AND PURPOSE OF HOME CHEMOTHERAPY FOR CANCER

1.2.1 Scope of this report

As mentioned above, we use the term 'home chemotherapy' to denote any type of administration of cancer chemotherapeutic agents at home (intravenous, subcutaneous, oral, etc.), with or without on-site supervision by a nurse. Furthermore, we restricted our literature search to chemotherapy for cancer *control and cure,* rather than end-of-life cancer care (where chemotherapy can have a role in palliation of pain and other symptoms). We also place our emphasis on cancer treatment for adults in this report. While we have included the pediatric literature on home chemotherapy (which is relatively extensive), we did not focus our review on children since childhood cancer remains very rare (in 2000, 311 cancer cases were diagnosed in Québec among those 0-19 years old [Fichier des tumeurs: msss.gouv.qc.ca/statistiques/tumeurs.html]). However, since many pediatric cases require chemotherapy for long periods (for example, the most common childhood cancer, acute lymphoblastic leukemia or ALL, generally has a 2-3 year maintenance treatment phase; www.cancernet.nci.nih.gov), we extended our interviews with clinical teams to include urban teaching hospitals for children in two provinces, Québec and Ontario.

1.2.2 Definition of home chemotherapy for cancer

Chemotherapy involves the administration of cytotoxic drugs that prevent the growth and proliferation of cells, and is especially used in cancer treatment in order to destroy tumour (neoplastic) cells that show uncontrolled growth [SBU, 2001]. This treatment is often combined with other antineoplastic strategies, such as surgery and radiotherapy. Chemotherapy can be used to cure cancer or control its spread, and can also be used in end-of-life care as a palliative measure, to relieve symptoms in those with advanced disease for whom prognosis is poor (i.e. terminal cases) [SBU, 2001].

In our background research for this report, we made extensive use of a comprehensive review of cancer chemotherapy published in 2001 by SBU, the Swedish Council on Technology Assessment in Health Care. According to this report, there is good evidence, in general, on the clinical effectiveness of chemotherapy in the available scientific literature. For some cancers chemotherapy may be the only treatment offering cure (e.g. Hodgkin's disease, acute myelogenous leukemia, and aggressive non-Hodgkin's lymphoma), while for breast and colon cancer, chemotherapy can often cure if combined with surgery/radiation. In other cases, chemotherapy has controlling effects and can extend life without signs of disease for many years (e.g. mild non-Hodgkin's lymphoma and chronic lympocytic leukemia). In advanced or metastasized cancers, chemotherapy has been shown to alleviate symptoms and can extend survival (e.g. for advanced disease in the pancreas, stomach, breast, colon, rectum, ovaries, bladder, and non-small cells of the lung) [SBU, 2001].

Home chemotherapy has been defined as "a service that provides a package of care to support the administration of chemotherapy to patients in their homes by specialist health care professionals (usually nurses)" [Young and Kerr, 2001, p. 810]. For this report, we interpret this definition to include any modality of chemotherapy delivery in the home setting (intravenous, oral, intramuscular, subcutaneous), whether

there is constant on-site supervision by a nurse or not, as previously discussed. The premise behind home chemotherapy is that cancer patients may prefer to receive their treatments at home, if it is possible to do so, rather than in hospital (usually as day patients or in an outpatient department) or in a medical clinic. This care delivery model has significant implications for the patient, those who live with him/her, informal caregivers (e.g. family members, friends, neighbours), and professional care providers involved in home care. The approach can be appealing to the patient for a number of reasons including receiving therapy in the comfort and security of the home; decreased travel to medical facilities; reduced risk of nosocomial infections (acquired in hospital); an increased sense of control over treatment and illness; and less disruption of family life [Dougherty et al., 1998; Gorski and Grothman, 1996].

As will be discussed in detail in a later section, home chemotherapy is also generally thought to be able to reduce health service costs by decreasing the need for hospital facilities, although costs of care may be merely shifted from professional health workers (paid by institutions) to informal caregivers (costs paid by patients) [King et al., 2000; Lowdermilk, 1995]. Different home care models give more or less responsibility to informal caregivers to assist the patient and deliver the chemotherapy, with varying levels of supervision by nurses visiting the home, and different requirements for medical check-ups in terms of frequency and location. For curative chemotherapy, home treatment is carried out for a scheduled time period as part of a physician-supervised treatment plan; in palliative settings, home chemotherapy is related to the dying-at-home choice and quality of life in the face of terminal illness (at the individual patient level, however, these two uses of chemotherapy may overlap) [SBU, 2001].

1.2.3 Cancer patient groups for whom home chemotherapy is possible

As will be described further below, recent advances in cancer treatment modalities and technological improvements have made it possible to offer chemotherapy in the home under strict conditions, related to specific course(s) of treatment required; caregiver availability, motivation, and training; the home environment and location; and patient characteristics (e.g. capacity to be trained in self-care, severity of cancer stage, co-morbid illness) [Dougherty et al., 1998]. Thus, not all cancer patients *will be eligible to consider* home chemotherapy as an option, an equity of access issue which we will discuss in section 5 of this report. Based on our literature review and clinical interviews (sections 3 and 4), in general most home chemotherapy treatment plans require frequent medical evaluation and blood tests (at home or at a clinic or hospital); a venous access device (see below); prior chemotherapy administration in hospital; and residence within a certain distance of a hospital or cancer centre/clinic.

In the case of children with cancer, home chemotherapy can be administered by suitably trained parents [Hooker and Kohler, 1999; Jayabose, 1991]. Alternatively, home care nurses can administer the treatment and parents can be trained to recognize complications [Holdsworth et al., 1997]. The elderly can be thought of as a special group in that cancer is a common medical problem (70% of all new cancer cases in Canada occur among those 60 years and older; [NCIC, 2001], and certain characteristics may make chemotherapy in general more complicated and less efficacious (e.g. co-morbid illness, decreased physical strength, increased susceptibility to adverse drug reactions, reduced renal excretion); however, many treatments can be administered to elderly at home given appropriate supervision and support [McKenna, 1994].

The specific types of cancer that can be treated by home-based chemotherapy depend on the type of therapy required (e.g. specific agents used, method of administration, duration of drug delivery). Many treatment protocols cannot be administered outside of a hospital setting. When reading this report, it should be kept in mind that the oncologist's goal is to prescribe the protocol that is thought to be the most effective for a particular patient's case; location of treatment delivery is thus secondary to clinical benefit. As will be discussed further, when a protocol that can be delivered at home is prescribed, the important factors to be considered regarding a patient's eligibility for home treatment relate to the patient's acceptance of—and ability to cope with—home care, the availability of assistance at home (both professional and informal), and the suitability of the home environment.

1.3 OVERVIEW OF HOME CHEMOTHERAPY FOR CANCER

1.3.1 Administration of chemotherapy in the home

Cancer chemotherapy is usually administered in treatment cycles, with non-treatment "rest" periods (of several days or weeks) in between to allow non-tumour cells to recover from its cytotoxic effects [SBU, 2001]. Doses may be given for several (or many) consecutive days or every other day, and more than one drug (combination chemotherapy) is usually prescribed [Regroupement des pharmaciens en oncologie, 2001; ACS, 1999]. Depending on the particular case, cycles can be repeated 6-9 (or even more) times over treatment periods of 4-6 months, although shorter and longer protocols are followed [Regroupement des pharmaciens en oncologie, 2001; SBU, 2001]. As cancer chemotherapy drugs have a narrow range of safe and effective doses, these must be calculated and administered with great precision [ACS, 1999].

The specific treatment plan (e.g. drugs prescribed, delivery regimen, length of therapy) depends on the kind of cancer and where it is found, the degree of spread of the cancer, the effect of the disease on normal body functioning, the general health status of the patient, how the body responds to the chemotherapy, and the therapeutic goals [NCI, 1999]. Currently, chemotherapy is more commonly used for breast cancer, several cancers of the blood or lymphatic systems (e.g. acute myelogenous leukemia, chronic lymphocytic leukemia, Hodgkin's disease), and increasingly for colorectal cancer, non-small cell lung cancer, and malignancies in the pancreas, bladder, and gastric system [SBU, 2001]. It should be kept in mind, however, that treatment protocols evolve as clinical research and practice continues over time.

Cancer chemotherapy can be administered in many different ways, including orally, intramuscularly, topically as a cream or lotion, subcutaneously, intrathecally (into the cerebrospinal fluid), and intralesionally (directly into the tumour); however, the most common method is intravenously (into a vein) as the drugs can be very irritating or damaging to skin, muscle, and the digestive system [ACS, 1999]. In the hospital setting, most cancer patients receive chemotherapy as outpatients and are not admitted, for drugs received as an intravenous push, intravenous short infusion, or as an injection [ACS, 1999; Pfister, 1995]. The intravenous (IV) method allows for prolonged treatment (e.g. 24-72 hours of continuous drug infusion) and multi-day protocols, using an electronic pump or a series of balloon infusors. Continuous infusion appears to increase the efficacy and/or decrease the toxicity of several chemotherapy drugs, such as cytarabine, doxorubicin, ifosfamide, bleomycin, cytosine arabinoside, and 5-fluorouracil [Meta-Analysis Group in Cancer, 1998; Holdsworth et al., 1997; Parker, 1992; Mioduszewski and Zarbo, 1987].

Intravenous infusion chemotherapy can be used in the home setting, where the drugs can be administered by the patient, a nurse, or informal caregiver [Catania, 1999; Parker, 1992]. We include short-term (e.g. up to 2 hours), medium-term (e.g. 2-12 hours), and multi-day continuous infusions in this report if home-based, with or without on-site delivery or supervision by a nurse. We also consider other routes of administration used in the home, including single, intermittent injections and oral therapy [Catania, 1999; Ron et al., 1996; Parker, 1992]. When a

continuous, multi-day infusion is prescribed (the most common being a 3 to 5-day infusion of 5-fluorouracil for several solid tumours including colorectal, stomach and breast cancer), the alternative to home chemotherapy is *inpatient* hospitalization [Pfister, 1995].

For IV delivery, a thin needle is placed into a vein in the hand or lower arm for each treatment session; if many treatments are needed, a catheter is inserted into a large vein in the chest, neck or arm and remains in place for as long as necessary for drug administration and taking blood samples (to monitor bone marrow function) [NCI, 1999]. The catheter can be attached to a port placed under the skin and can also be combined with a pump to control the chemotherapy flow rate (either an external, portable pump or one that is internally implanted during surgery) [NCI, 1999; Dougherty et al., 1998]. Cancer patients often have to receive other substances by infusion, including anti-emetics (to control nausea and vomiting), antibiotics (to treat infections), hydration (to replace fluids), and nutrients (to manage nutritional deficits) [ACS, 1999; Gorski and Grothman, 1996]. Table 1 summarizes the different types of venous access devices used for intravenous administration of chemotherapy and other substances.

Complicated chemotherapy regimens may require hospitalization, and certain patients may have to be closely monitored in a hospital setting due to the specific drugs/doses used or their general health state [ACS, 1999; Parker, 1992]. A number of chemotherapy drugs are vesicants, meaning they are extremely injurious to the skin and muscle tissue if they leak out of a vein, and must be administered with a venous access device (which is more stable than a regular IV), regardless of the setting [ACS, 1999; Chrystal, 1997]. Because side effects from either outpatient or home treatment will tend to develop at home, the major safety issues specific to intravenous home chemotherapy relate to the risk of extravasation and technical management of the equipment.

TABLE 1

Types of venous access devices

TYPE OF DEVICE	COMMENTS
PICC (peripherally inserted central catheter)	Allows for continuous access to peripheral vein for several weeks (and up to 6 months). No surgery needed. Care of catheter needed. Potential for infection less than for TCVCs.
Midline catheter	Catheter not inserted as far as a PICC. Used for intermediate length therapy when a regular peripheral IV is not advisable or available.
TCVC (tunnelled central venous catheter)	Catheter with multiple lumens (channels) surgically placed in large central vein; catheter tunnelled under skin. Care of catheter needed. Catheter entry into vein is removed from exit site on skin, decreasing risk of infection.
Implantable venous access port	A port (plastic/stainless steel/titanium) with a silicone septum accessed by a needle to give chemotherapy; catheter surgically placed under skin of chest/arm in a large or central vein. Needle can remain *in situ* for up to 7 days.
Implantable pump	A titanium pump with an internal power source surgically implanted, for continuous infusion chemotherapy (using refillable reservoir).
External pump	A pump (usually battery-operated) that remains outside the body; most are portable and allow the patient to move around while in use.

Sources: ACS, 1999 (www3.cancer.org/cancer_info) accessed 2001-08-01; NCI, 1999 (cancernet.nci.nih.gov) accessed 2001-08-01; Campbell, 2000; Regroupement des pharmaciens en oncologie, 2001

1.3.2 Potential side effects and complications of chemotherapy

Cancer chemotherapy drugs injure normal cells as well as tumour cells, thus treatment is associated with a high risk of adverse effects [SBU, 2001]. Common side effects include damage to the gastrointestinal tract (nausea, diarrhea, constipation, vomiting, and mucositis, an inflammation of the lining of the mouth, throat or esophagus), headaches, loss of appetite and malnutrition, myelodepression (thrombocytopenia, neutropenia—leading to susceptibility to infections—anaemia), fatigue, liver and kidney damage, hair loss, menstrual cycle disruption, and nervous system injury [SBU, 2001; ACS, 1999; Berman, 1999]. The severity of side effects is extremely variable, depending on the drug(s) used, schedule of administration, dosage, and the individual patient [NCI, 1999].

Most side effects are temporary, as the normal cells repair themselves once chemotherapy is stopped; however, some of the symptoms can continue and become chronic [ACS, 1999; NCI, 1999]. In some cases, chemotherapy can cause permanent damage to the heart, lungs, bladder, kidneys, nervous system, or reproductive organs (e.g. sterility) [ACS, 1999; NCI, 1999]. Neurological changes can develop months or years after treatment, and include impaired memory, personality changes, numbness in the hands and feet, shortened attention span, hearing loss, or seizures [ACS, 1999]. Chemotherapy in young children can impair learning abilities and growth [ACS, 1999].

Most patients tire easily when receiving chemotherapy; however, many lead active lives and continue to work (although a reduced schedule is often necessary) [NCI, 1999]. The fatigue that can be experienced by a cancer patient is generally not resolved with rest or sleep and can be felt as a complete lack of energy, weakness, weariness, inability to concentrate, and forgetfulness, affecting his/her quality of life, and requiring modifications to usual lifestyle [ACS, 1999; NCI, 1999]. Severe fatigue usually subsides as the cancer responds to treatment [NCI, 1999].

Complications related to the devices used for infusion chemotherapy are an important risk [Dougherty et al., 1998]. Potential problems with the catheter include extravasation of the drugs (where drugs infiltrate the tissue surrounding the catheter entry site), infection at the entry site, and clotting or occlusion of the catheter and the vein [Campbell, 2000; Dougherty et al., 1998; Cox et al., 1997]. A blood clot in the lumen can be caused by pump failure/malfunction or inappropriate catheter flushing (incorrect solution or technique) [Dougherty et al., 1998]. If the clot becomes infected or a thrombosis forms, the device must be removed [Campbell, 2000]. With a pump, complications can arise from rupture or leak of the drug reservoir, improper flow rate, or battery depletion or failure [Dougherty et al., 1998; Cox et al., 1997]. Improper catheter insertion can lead to dysrythmias, pneumothorax, or an air embolism [Campbell, 2000]. The most common complication from central venous catheters is infection, which can be very risky for an immuno-compromised patient [Campbell, 2000].

1.4 HISTORICAL DEVELOPMENT

1.4.1 Development of this intervention and transfer from the hospital to home setting

Chemotherapy drugs to treat cancer were first discovered in the 1940s (e.g. mustard gas), with the first organized research studies commencing in the mid-1950s [ACS, 1999; Creel et al., 1996]. Since the mid-1970s there have been rapid advances in clinical knowledge and oncology nursing has been established as a speciality [Creel et al., 1996]. As infusion therapy methods developed in the 1980s, outpatient departments and ambulatory treatment clinics were increasingly used for cancer chemotherapy [Dougherty et al., 1998]. Home infusion therapy began about 20 years ago in the United States, and about 90% of American cancer care is now delivered in outpatient settings, including home [Creel et al., 1996]. It was estimated that over 100,000 cancer patients would receive infusional home chemotherapy annually in the US by 1997 [Gorski and Grothman, 1996]. Data on the percentage of cancer patients currently receiving home

chemotherapy across Québec were not readily available at the time of this report; a province-wide survey of oncology departments would be required to obtain such figures.

The movement of cancer chemotherapy into the home was facilitated and influenced by a number of factors. Briefly, these include [Dougherty et al., 1998; Gorski and Grothman, 1996; Lowenthal et al., 1996; Pfister, 1995; Thickson, 1993]:

- increased costs of hospitalization;
- a general need to reduce hospital use and length of stay through earlier discharge and ambulatory treatment methods (related to financial constraints, the introduction of prospective payment systems for hospital services in the US, and other cost-containment strategies);
- ageing populations and improved cancer survival rates;
- technological advancements in infusion therapy, venous access devices, and portable infusion pumps;
- improvements in nausea control;
- development of less toxic chemotherapy drugs;
- development of palliative methods to facilitate less painful dying at home;
- initiative of nurses and pharmacists and the development of home care agencies (particularly in the US).

The future use of home chemotherapy will continue to be influenced by technological improvements that increase clinical effectiveness and/or safety. The development of more sophisticated methods of monitoring patients' status or programming infusion pumps from a distance could have an important effect [Pfister, 1995], particularly with respect to increasing access to home chemotherapy in rural areas. A rural regional cancer centre in Ontario has recently been involved in pilot testing of an infusion pump whose operation can be remotely controlled using a modem and telephone line[1].

On the basis of the literature reviewed for section 3, it appears that several European countries (e.g. Germany, The Netherlands, France, Greece), United Kingdom, Japan, and Australia currently provide some level of chemotherapy services to cancer patients in the home. Based on our interviews in Québec and Ontario, availability of home chemotherapy in these provinces appears quite limited. For the purposes of this report, we have focused our investigation of the current use of home chemotherapy to its provision at selected sites in Québec (see section 4). We extend our analysis in section 4 to Ontario, in order to make a comparison with a province that has similar demographics but a markedly different organizational structure for cancer care.

1. Personal communication with K. Hughes, December 21, 2001

2 OBJECTIVES AND METHODS

2.1 QUESTIONS ADDRESSED BY THIS REPORT

This report examines the issues surrounding home cancer chemotherapy for patients, caregivers (both professional and informal), and the health care system. We use the term 'home chemotherapy' to denote any type of administration of chemotherapeutic agents at home (intravenous, subcutaneous, oral, etc.), with or without on-site supervision by a nurse. Examples thus include short-term infusions delivered at home by a nurse, multi-day continuous infusions started by a nurse at a hospital and continued without a nurse being present at home, oral therapies taken at home, and injections delivered by parents in the home to a child with cancer. In particular, the different sections of this document explore the following:

(1) Can the home delivery setting affect the clinical benefit of cancer chemotherapy?

(2) Does home chemotherapy reduce costs and, if so, for whom?

(3) Can home chemotherapy be delivered safely?

(4) What are its quality of life implications for the cancer patient?

(5) What are its organizational implications for the health care system?

(6) What are its ethical, legal, and social implications for the health care system and for society?

(7) Does its viability as a service differ depending on patient and regional characteristics?

(8) What alternatives to home chemotherapy should be available?

2.2 METHODS

The following methods were used in the development of this report:

(1) Search and review of the scientific literature (English or French), based on PubMed (Medline 1980 – August, 2002) and CancerLit (1975 – August, 2002) bibliographic databases, using ("home" OR "domiciliary" OR "outpatient") AND "chemotherapy" AND "cancer" as search terms. The CancerLit database was also searched using the terms "patient" AND "cancer chemotherapy" AND ("quality of life" OR "psychology"). For additional Canadian-based information for section 5 (organizational, ethical, and legal issues), PubMed (Medline 1980 – August, 2002) was searched using the terms "oncology" AND "Canada", as well as "cancer care" AND "Canada" AND "organization". MedlinePLUS was used to find patient information booklets on cancer chemotherapy. The Clinical Medicine section of Current Contents and the reference lists of retrieved articles and documents were also implemented. We excluded studies that focussed on terminally ill patients receiving palliative chemotherapy. We also excluded studies of home-based high-dose chemotherapy and stem cell rescue as a treatment for metastatic breast cancer and other cancers, as this practice is currently considered inappropriate in Québec and elsewhere[2].

(2) Semi-structured qualitative interviews with service providers/administrators from hospital, health system, and community settings in Québec and Ontario (see Appendix for interview guide). The goal of the interviews was not to obtain an exhaustive survey of home chemotherapy programs across Québec (nor across Ontario), but rather to collect perspectives on the benefits, barriers, facilitating factors, and challenges in providing these services in diverse settings. It is important to acknowledge the existence of other home chemotherapy programs not included in

2 Personal communication with J. Latreille, August 29, 2003

our sample. We included Ontario in order to make comparisons with interview data from a province with similar population and geographic distribution but a different organizational structure for cancer care.

A total of 17 interviews were completed between May, 2001 and March, 2002, representing 16 different institutions/organizations: six urban university teaching hospitals in Québec (Montréal and Quebec City), an urban general hospital in Québec, an urban cancer hospital in Ontario, two urban pediatric hospitals (one each in Québec and Ontario), three regional cancer centres in Ontario (one of these in a remote area), two rural hospitals in Québec, and Cancer Care Ontario. One of these interviews was with a representative from the *Conseil québécois de lutte contre le cancer*, non part of the new DLCC (who worked at one of the rural Québec hospitals). In most cases these interviews were completed with head nurses, but two oncologists, three community care nurses, a family physician, and a team of outpatient oncology nurses were also included. Four interviews were conducted by telephone, and one by electronic mail. Notes from the interviews were analyzed for descriptive information and recurring themes [Murphy et al., 1998].

3 EVIDENCE FROM THE LITERATURE ON BENEFIT, COSTS, AND SAFETY

3.1 CLINICAL EFFICACY/ EFFECTIVENESS

3.1.1 Effect of delivery setting on the clinical efficacy/effectiveness of chemotherapy

As indicated by Lowenthal and colleagues, there is no clinical reason for efficacy to be negatively affected by home chemotherapy, if the same treatment regimen is administered at home and at a hospital (or clinic), and assuming the delivery method is carried out properly (e.g. correct dose and technical procedures) [Lowenthal et al., 1996]. In fact, it is possible that home treatment could have superior clinical effect through the decreased risk of nosocomial infection in the home and if the home setting promotes a more positive patient attitude that improves clinical outcome. In the United States, it has also been suggested that delays in starting therapy on schedule are more likely to occur in the hospital setting [Holdsworth et al., 1997; Lange et al., 1988]. Adverse side effects (e.g. nausea and vomiting) have been seen to greatly decrease in frequency in the home environment [DeMoss, 1980]. However, direct evidence of the above factors affecting clinical outcome in home chemotherapy is not documented in the literature.

3.1.2 Evidence regarding clinical benefit of home chemotherapy

We searched for articles in the scientific literature that have examined the efficacy or effectiveness of chemotherapy delivered at home compared to non-home settings, according to clinical outcomes such as survival rates, remission rates, and tumour control. It became clear that the emphasis in the research milieu has not been on clinical efficacy or effectiveness in the home setting, but rather on associated costs, safety, patient preference, and effects on psychosocial factors (the larger body of evidence will be presented in later sections). This could be related to the fact that certain regimens, such as long-term continuous infusions (e.g. multi-week) or oral chemotherapy, may not be offered in any setting other than the home.

3.1.2.1 RANDOMIZED CONTROLLED TRIALS

We identified eight randomized controlled trials of home chemotherapy in the scientific literature. Six of these examined such outcome measures as costs, toxicity, safety, treatment compliance, and patient quality of life, preferences, and satisfaction. Only two trials included clinical measures, but these were in the form of pharmacokinetic analysis [Borner et al., 2002; Vokes et al., 1989]. When comparing two drug delivery devices (a standard inpatient pump versus a portable system, which could be used at home), Vokes and collaborators found no significant differences in the average plasma concentrations of the continuously-infused chemotherapy drug (5-fluorouracil for 5 days), based on 19 American patients who had used both systems once (median age 56 years) [Vokes et al., 1989]. Of the 19 crossover patients, who all had locally advanced head and neck cancer, 11 used the portable system at home. The plasma level outcome considered in this study is clearly an indicator of drug delivery function rather than a direct marker for treatment success. The evaluation of clinical response to the chemotherapy was not analyzed according to device, since all patients used both systems. In the multi-site European trial by Borner and colleagues, the pharmacokinetics of *intravenous* 5-fluorouracil (5-FU) by daily bolus injections plus leucovorin (for 5 days every 4 weeks, administered at an outpatient facility) were compared with a daily *oral* fluoropyrimidine formulation (containing tegafur, which converts to 5-FU) plus oral leucovorin taken at home (3 times/day for 28 days every 5 weeks) [Borner *et al.*, 2002]. Thus the same treatment protocol was not compared in the two settings.

3.1.2.2 Controlled studies

A study conducted in Israel likewise compared 35 home care patients with colorectal cancer using *oral* chemotherapy (daily ftorafur with leucovorin) with 26 clinic patients with less advanced colorectal cancer who received leucovorin and *intravenous* infusions (5 days) of the more toxic 5-fluorouracil (5-FU), from which ftorafur is derived [Ron et al., 1996]. There was significant improvement in functional status after 3 and 6 months in the home care patients and no statistically significant differences in the proportions of patients surviving in the two treatment groups (despite more advanced disease in the home group). These findings are suggestive of a beneficial effect of either oral ftorafur or the home setting (or both), since the home-treated group was expected to have shorter survival due to their more advanced disease.

3.1.2.3 Uncontrolled studies

We found several uncontrolled studies which reported on clinical response for cancer patients treated at home but none of these presented comparable data for the same treatment regimen in an institutional setting. Two of these studies studied oral chemotherapy, and compared clinical response to that obtained by other researchers and clinicians via radiotherapy [Spatti et al., 1987] or intravenous 5-FU treatment [Falcone et al., 1994]. Atzpodien and colleagues compared cellular response to self-administered *subcutaneous injections* of low dose interleukin-2 and interferon-α 2b with reported figures for high-dose *intravenous* regimens of interleukin-2 received in hospital [Atzpodien et al., 1990]. Collichio and colleagues provided no comparative data for their study of 1-hour paclitaxel (outpatient) infusions plus two 4-day low dose 5-FU infusions by pump at home for 21 patients with recurrent or metastatic breast cancer [Collichio et al., 2002]; their failure to meet a target response rate of 60% was unlikely to be related to the location of the therapies.

3.1.2.4 Conclusions

Based on our search of the literature, there is a lack of solid evidence either for or against clinical benefit of home chemotherapy compared to non-home settings. The only randomized controlled trial we identified focussed on drug delivery function rather than treatment success. The rest of the studies we found aimed at testing a treatment protocol rather than examining the effect of different therapy settings.

3.2 ECONOMIC EVALUATION

3.2.1 Financial implications of home chemotherapy

As noted by King and collaborators, home chemotherapy can require purchase of some specialized equipment and usually involves greater nursing time for travel and treatment delivery; on the other hand, clinic or day-ward space is made available in the hospital or outpatient centre [King et al., 2000]. Costs of providing drugs for home chemotherapy may differ when supplied and prepared by community versus hospital pharmacies [Thickson, 1993]. Pharmacy costs will, in general, be less when drugs are prepared in large batches for many patients. In some cases (e.g. multi-day continuous infusion), overnight hospital admission can be prevented by sending the patient home with a programmable pump, which can result in large cost savings for the specific patient's care from the perspective of the hospital. Given that the vast majority of chemotherapy treatments for adult cancer patients (not including acute leukemia) can be delivered in outpatient settings[3], the comparison of outpatient versus home care costs is particularly important. Costs to patients and their families could be affected in several ways: there may be lost income if home treatment requires someone to give up paid employment for caregiving [Stommel et al., 1993; Arno et al., 1995]; on the other hand, fewer trips to clinics/hospitals for treatment (or to visit a hospitalized family member) means savings in terms of travel and accommodation expenses, and possibly less loss of wages.

3. Personal communication with G. Batist, July 19, 2002

In the section below, we present home chemotherapy studies that included a consideration of costs according to their study design. For each study, we identify whether comparisons were made to inpatient or outpatient settings; this choice depended on where the specific treatment(s) considered would normally be administered at the time (if not at home). Table 2 presents a summary of the findings. Shaded in grey are the cost differences for the eight studies that compared home care to either outpatient care only, or to a combination of out- and inpatient care (depending on patient eligibility). Six studies compared home care to inpatient treatment (unshaded). This table also indicates the type(s) of treatment considered, sample sizes for each study, and the analysis perspective. A total of four studies took place in the pediatric cancer setting [Holdsworth et al., 1997; Close et al., 1995; Jayabose et al., 1992; Lange et al., 1988].

3.2.2 Evidence regarding costs compared to institutional chemotherapy

3.2.2.1 Randomized controlled (crossover) trials

In an American randomized controlled trial of 22 crossover adult patients with head and neck cancer, the costs of home infusion from a hospital perspective were *less* than *inpatient* therapy by $366 US per day of treatment [Vokes et al., 1989], although the comparison only considered pharmacy charges, device costs, and the relative length of hospital stay (2 versus 6 days, respectively; nursing costs were not mentioned). Rischin and colleagues found that the home site cost $83 AUS *more* per treatment cycle than *day-ward* therapy (from a hospital perspective) for 20 Australian crossover patients with cancer of the breast, colon, pancreas, or non-Hodgkin's lymphoma ($p<0.001$) [Rischin et al., 2000]. King and collaborators showed that the marginal cost from a system perspective was $69 AUS *greater* per treatment in the home setting versus *day hospital*, for 40 Australian crossover patients with breast, colon, or head/neck cancer [King et al., 2000]. In both Australian studies, the greater costs were largely due to increased nursing time [Rischin and Matthews, 2001; King et al., 2000]; in Australia, most chemotherapy in the hospital setting is provided in outpatient clinics or day wards [King et al., 2000]. The two Australian studies appear to be of high quality, although this is easier to judge for the publication by King and collaborators, which provides extensive study details.

In the analysis by King and colleagues described above, the home chemotherapy service was added to the existing services of the oncology day ward without additional resources [King et al., 2000]. These researchers carried out a second analysis in which they considered the costs of expanding the hospital chemotherapy services to meet increasing patient demand, versus the costs of providing home treatment for suitable patients. For a projected increase in workload of up to 50 percent of present ward capacity, the total additional cost of day hospital services per treatment would be greater than the costs of home chemotherapy [King et al., 2000].

An RCT with 42 crossover patients in France (the majority having breast cancer) similarly found a *higher* marginal cost for the home setting (by $75 US per treatment compared to *day hospital*, $p<0.001$), but found a *lower* average cost when including overhead costs, by $25 US per treatment ($p<0.001$) using a societal perspective for both analyses [Remonnay et al., 2002, 2001]. The investigators used a questionnaire to collect data on private costs to patients and their family members (such as extra expenses, lack of free time, additional housework or fatigue, and obligations to be present in the home); since both patients and family members reported these costs to be the same for home or day unit treatment, this category was excluded from the analysis. Transport costs to hospital were estimated as if all patients used taxis or medical vehicles. The home program was organized differently than typical services in Québec (see section 4) since personnel costs included a family physician visit prior to treatment, household help during therapy, a social worker visit, home care coordination, and the cost of a nurse remaining with the patient during the entire treatment [Remonnay et al., 2002].

TABLE 2

Summary of cost studies

STUDY / TYPE OF TREATMENT(S) / N (SAMPLE SIZE)	COSTS OF HOME CARE	COMPARISON CARE SITE	ANALYSIS PERSPECTIVE
RCTs (all crossovers)			
Vokes et al., 1989 / intravenous / 22	- $366/day US	inpatient	hospital
Rischin et al., 2000 / intravenous / 20	+ $83/treatment AUS ($p<0.001$)	day ward	hospital
King et al., 2000 / intravenous and oral / 40	+ $69/treatment AUS (marginal cost)	day ward	system
Remonnay et al., 2001, 2002 / intravenous / 42	+ $75/treatment US (marginal; $p<0.001$) - $25/treatment US (average; $p<0.001$)	day hospital	society
Cost models			
Grusenmeyer et al., 1996 / intravenous / ns	+ $548-1,100 US total costs ($p<0.05$) + $70-650 US total costs, excluding drugs	outpatient	hospital
Mioduszewski and Zarbo, 1987 / injections and intravenous / ns	- $5,174 US total costs	inpatient	hospital
Controlled studies			
Malone et al., 1986 / intravenous / 15 crossover	- $31/course of treatment* US	inpatient	hospital
Lowenthal et al., 1996 / intravenous / 65 vs 119	+ $5/patient AUS (marginal) - $66/patient AUS (average)	day ward	hospital
Ron et al., 1996 / oral (home) vs intravenous (non-home) / 35 vs 26	- 70% total cost per patient over 1 month	inpatient (if resided far away) or outpatient	hospital
Serrate et al., 2001 / types not specified / 10 vs 10	- $18,337 US total costs (p not significant) - $132/patient US (mean daily costs; $p<0.001$)	outpatient or inpatient	third party payer
Close et al., 1995 / intravenous / 14 crossover PEDIATRIC	- $464/day US medical charges ($p<0.01$) - $57/day US out-of-pocket costs ($p<0.005$) - $198/day US lost income ($p<0.001$)	inpatient	patient
Uncontrolled studies			
Lange et al., 1988 / intravenous / 22 PEDIATRIC	- $822-2,631/treatment regimen US	inpatient	hospital
Jayabose et al., 1992 / intravenous slow push & infusions / 20 PEDIATRIC	- $5,866/patient US	inpatient (for infusions) and outpatient	hospital
Holdsworth et al., 1997 / intravenous / 44 PEDIATRIC	- $367-5,180/course of treatment* US (medical costs only)	inpatient	patient and/or third party payer

*We have retained the phrase "course of treatment" here and in the text of this report when used by the study authors. In these articles, *course of treatment* can mean a series of treatment cycles, or one cycle of treatment.

ns=not specified (for sample size in cost models).

Shaded areas denote comparisons between home care and outpatient care only, or between home care and a combination of out- and inpatient treatment. If no p value is indicated in the table, no results of statistical testing were reported in the source publication.

3.2.2.2 COST MODELS

In conference proceedings for the American Society of Clinical Oncology, Grusenmeyer and colleagues report on a cost comparison of home care versus *outpatient* clinic treatment for four chemotherapy regimens (for colon, breast, and lung cancer and including continuous 5-FU infusion), based on experiences and costs in their US clinic and an affiliated home care agency[4] [Grusenmeyer et al., 1996]. Depending on the treatment regimen, home care was from $548 US to $1,100 US *more* expensive ($p<0.05$), considering staff requirements (treating and support personnel), drugs and supplies, and overhead costs (space and utilities). When drug costs were excluded, home care was still *more* expensive (by $70-650 US) due to higher personnel costs at the home care agency where one nurse had to be allocated per patient; in the outpatient infusion centre, one nurse cared for several patients at a time. The conference proceedings and personal communication with the author did not provide enough information to assess the comparability of the patients in the two settings.

An article on ambulatory infusion pumps presented *inpatient* versus home care costs for a course of chemotherapy for leukemia on the basis of 1985 hospital bills at the University of Michigan Medical Center [Mioduszewski and Zarbo, 1987]. The treatment regimen included 3 days of daunorubicin injections and 7 days of continuous cytosine arabinoside infusion. The total cost of 8 inpatient days (based on charges for an inpatient room, pharmacy, lab, and x-ray) equalled $6,549 US, whereas the home protocol, comprised of 4 days at home and 3 clinic visits for injections, totalled $1,375 (no $3,590 room charge, $1100 less for pharmacy, $575 less for lab, no $359 x-ray charge, $125 for pump rental, $325 for clinic charges). The article makes no mention of relative personnel costs in the two settings, and no details are provided to explain the reduced pharmacy and lab charges. Data on relative expenses borne by patients were not collected, but it is suggested by the authors that out-of-pocket costs are greater for inpatients.

3.2.2.3 CONTROLLED STUDIES

In a small study of 15 crossover patients with gynecologic cancer in USA, combination chemotherapy was first received in hospital (either as *in- or outpatients*) and the patient's subsequent treatment was administered at home by a visiting nurse [Malone et al., 1986]. If necessary, home visits were made following chemotherapy, on the basis of the nurse telephoning for the patient's status. The fees at the teaching hospital for overnight admission for chemotherapy delivery were $1,029 US per course, compared to $998 US for the same therapy at home (thus *less* expensive at home by $31 per course). No other financial details were provided by the authors.

A controlled study of Australian patients (with various cancer types) compared costs to the hospital of providing chemotherapy at "home" to 65 patients (by an oncology nurse) versus in the hospital *day ward* to 119 patients over one year [Lowenthal et al., 1996]. A minority of patients in the "home" group received treatment in the workplace, a general practitioner's office, or day care centres, which is not typical in Québec. Although the relative proportions of different cancer diagnoses in the two groups were not identical, the authors state that the general range of protocols delivered in the two settings was similar (the hospital protocols were not listed). The average direct cost to provide treatment was $66 AUS *less* per patient per year in the home setting, while the marginal cost (the extra cost of the home service, given the basic hospital service exists) was $5 *more* per patient at home. For the latter comparison of home care with hospital treatment, the authors assumed extension of clinic service hours into the evening and hospital admission for 8% of the additional patients.

In a controlled study of 35 home care and 26 hospital patients with advanced colorectal cancer in Israel, Ron and collaborators found that the home setting was 70% *less* expensive when comparing total costs per patient over one month

4 Personal communication with P. Grusenmeyer, November 8, 2001.

of treatment [Ron et al., 1996]. The researchers made a questionable assumption that one month of home visits by an oncology nurse (at least 2 visits per month) was equivalent to the costs of a day of oncology clinic care (no justification was provided). The home patients had more advanced disease and received oral ftorafur (with biweekly blood testing by a visiting oncology nurse), while the hospital patients (treated as *outpatients or admitted* if residing far from the medical centre) received intravenous infusions of 5-fluorouracil (5-FU), which is more toxic but three times less expensive per mg. The cost comparison was made by totalling 1 month of daily oral ftorafur ($56) and leucovorin tablets ($116) plus home nursing (made equal to the cost of 1 clinic day, $433), versus 5 days of intravenous 5-FU ($15) and leucovorin medication ($21) plus 5 clinic days ($433 × 5).

A recent cost-minimization study carried out in the Canary Islands compared a small home-care group of 10 cancer patients (with 24-hour telephone support) to a retrospective series of 10 control patients who had received similar treatments at similar frequency in hospital, either as *in- or outpatients*, during the same period [Serrate et al., 2001]. The home program was very atypical compared to Québec since an on-call physician was in charge of the home visits and the telephone support, and the home-care service team included two oncologists, one internist, and five nurses. Of the 10 patients treated at home, five received chemotherapy (four of these also received "palliative care") while five received palliative care only; neoplasms included myeloma and gastrointestinal, bronchial, breast, brain, and bladder cancer (54-84 years; mean age 76). Total numbers of home visits were 152 by physicians and 464 by nurses with average durations of 1.3 and 1.5 hours, respectively. No home patients were readmitted to hospital; "home hospitalization" was provided by a team of doctors and nurses for a total of 194 days (this service was distinct from the home visits mentioned above). In the control group, six patients received chemotherapy and palliative care (47-75 years; mean age 61) for non-Hodgkin's lymphoma and gastrointestinal, kidney, breast, and bronchial cancer; the remaining four patients had palliative care only. Control patients spent a total of 221 days as hospital inpatients.

Outpatient-type support received by home care patients was almost 13 times greater than that received by controls (582 days of home visits versus 45 outpatient visits, respectively; $p<0.025$), while intensity of inpatient-type care was similar. The total cost of home treatment (N=10) was 64% that of hospital care (N=10), although this difference was not statistically significant, and home care saved $18,337 US in total. Mean daily cost per patient was three times *lower* for home care ($p<0.001$; $61 US versus $193). Regarding direct costs, drug treatment costs were 6 times lower for the home-care group ($p<0.005$); it was suggested by the authors that this might be due to better coordinated, simpler treatment regimens being efficiently devised for each home patient. Total cost of testing (laboratory and radiology examinations) was similar in the two groups. Nursing time spent with home patients was 4 times longer ($p<0.01$), whereas doctor time was similar in the two groups. The telephone support service (273 physician minutes over 4 months) avoided 27 home visits, representing 35 working hours and saving $1,539 US; it should be noted, however, that this service was not charged and thus its costs were not included in the analysis, which would tend to decrease the difference between home and hospital costs.

Close and collaborators compared costs for 14 crossover pediatric patients with acute lymphoblastic leukemia (ALL; average age 8.75 years) in metropolitan Pennsylvania, USA [Close et al., 1995]. The first two chemotherapy courses were provided to the children as *inpatients* (usually requiring more than 48 hours of hospitalization) and identical subsequent treatments were administered at home by a nurse. Billed medical charges, out-of-pocket costs to the parents, and loss of parental employment income were significantly *less* for home treatment over one course of treatment by $464 US, $57 US, and $198 US per day, respectively ($p<0.01$; $p<0.005$; $p<0.001$).

3.2.2.4 UNCONTROLLED STUDIES

We found three uncontrolled studies that included costs of home chemotherapy as an outcome in the scientific literature; all of these studied treatment of children in the USA. Lange and colleagues calculated home care costs for 120 methotrexate infusions given to 22 ALL patients (aged 2 to 20 years) over 15 months: the home care program saved 357 inpatient days, reducing hospital costs by about half and costing about $822-2,631 US *less* than *inpatient* therapy [Lange et al., 1988]. For 20 children with various cancers (aged 2-18 years) who received 435 doses of chemotherapy at home during a 2-year period, Jayabose and collaborators found that 566 hours of clinic visits and 76 days of hospital stay, respectively, were saved for 17 patients receiving slow intravenous push (IVP) and 10 patients receiving intravenous infusion (IVI) [Jayabose et al., 1992]. Total cost *savings* amounted to $117,327 US, or $5,866 US per patient, based on *clinic visit* charges (for IVP) or hospital charges for *short-stay admission* (for IVI) versus service charges and drug/device costs at the home care organization. Holdsworth and colleagues studied 44 consecutive patients (aged 1 to 19 years) with various cancers (24 different treatment protocols) over a 3-year period [Holdsworth et al., 1997]. From the patient and/or third party payer (medical cost) perspective, home care provided by two local private agencies *saved* from $367 US to $5,180 US per course of treatment, depending on the protocol used, when comparing actual agency charges to typical *inpatient* hospital charges (not including physician fees). Total savings over three years were estimated at $640,793 (with a minimum of nearly $250,000 in sensitivity analysis).

3.2.2.5 CONCLUSIONS

Table 2 summarizes the results from the 14 identified studies which considered costs. No Canadian studies were found. As with the uncontrolled studies, most of the 9 comparative studies have small sample sizes, with less than half of these including 25 or more home patients. The five studies that used the same patients for comparison in a crossover design have greater methodological strength (for one of these, the delivery setting order was not randomized [Malone et al., 1986]). Across all studies, only two collected information on non-medical costs to patients [Remonnay et al., 2001, 2002; Close et al., 1995]. Remonnay and colleagues discarded such costs (with the exception of transportation) when patient and family questionnaires reported these to be the same in the two settings. It should be noted that the findings by Close and collaborators are applicable only to the pediatric setting.

A total of eight studies compared home care to either outpatient care only, or to a combination of out- and inpatient care (depending on patient eligibility; shaded cells in Table 2). Six studies compared home care to inpatient treatment (unshaded cells). Concerning the comparison of home and only *inpatient* chemotherapy, each applicable study found cost savings associated with home treatment from the hospital perspective. However, three of these studies were uncontrolled and took place in the pediatric setting. Of the three remaining studies [Close et al., 1995; Vokes et al., 1989; Mioduszewski and Zarbo, 1987], the American pediatric study by Close and colleagues appears to be the most valid despite the small number of crossover patients. Close and colleagues also demonstrated statistically significant savings for home treatment with respect to parental out-of-pocket costs and lost income. Thus, convincing evidence in support of cost savings for home chemotherapy when compared to inpatient therapy arises from only one pediatric study.

The direction of the results is mixed when home treatment is compared to outpatient therapy, or a combination of out- and inpatient treatment (where some patients were admitted overnight, usually due to their geographic location). Grusenmeyer and colleagues show the greatest difference in costs in favour of *outpatient* treatment, but the published abstract lacks sufficient information to evaluate this finding [Grusenmeyer et al., 1996]. Although all suggest lower costs in the home setting, the three studies that compared home therapy to a *combination* of out- and inpatient treatment consist of a pediatric study [Jayabose et al., 1992], an analysis with a questionable cost assumption [Ron et al., 1996], and an atypical

home program [Serrate et al., 2001] that included both home visits and a telephone support service by physicians. It is also surprising that despite the greater nursing time spent on the home care patients (4 times that of controls), Serrate and collaborators did not observe higher personnel costs associated with home treatment overall [Serrate et al., 2001].

When compared to *outpatient* treatment only, two of the four remaining studies found home chemotherapy to be slightly *more* expensive [King et al., 2000; Rischin et al., 2000]; in the other two studies, findings differed depending on whether marginal or average costs were considered, with *higher* marginal but *lower* average costs for home care [Remonnay et al., 2001, 2002; Lowenthal et al., 1996]. The choice of these two types of costs as an estimate depends on a healthcare institution's operating capacity, as average costs can be applied when capacity is full and increasing the number of patients requires expansion of facilities. Results were more favourable for the home setting when Remonnay and colleagues assumed home care could utilize the hospital pharmacy in their atypical program (marginal: + $13/treatment at home, average: – $87/treatment at home; results not shown in Table 2) [Remonnay et al., 2002].

Where home care was found to be more expensive compared to outpatient therapy, the additional cost components for home treatment by study were: nursing labor (care and coordination), nurse travel time, transportation, and special equipment for home administration [King et al., 2000]; personnel costs (care, especially by family physicians, and home care coordination) and medication costs (due to different purchasing methods) using marginal cost estimates [Remonnay et al., 2001, 2002]; and nursing time (care and travel), transportation, and special equipment for home administration using marginal cost estimates [Lowenthal et al., 1996]. Rischin and colleagues did not provide a breakdown of excess costs in their article [Rischin et al., 2000], but mention increased nursing time as a factor in a subsequent comment [Rischin and Matthews, 2001].

The mixed findings and variable study quality in the above comparisons of home chemotherapy programs with outpatient settings prevent a conclusion on the cost implications for the health care system. Several good studies provide different results depending on institutional operating capacity. Home chemotherapy appears to have a cost-shifting effect within the health care system. As chemotherapy moves into the ambulatory setting, there is potential for savings for inpatient departments which result in higher costs for outpatient hospital services; clinic costs are transferred to home care agencies and visiting nurse organizations when home care substitutes for outpatient treatment. Solid evidence for a financial effect on patients (particularly adults with cancer) is lacking in the scientific literature at present.

3.3 SAFETY

3.3.1 Safety issues arising from chemotherapy in the home setting

As introduced in section 1 of this report, home chemotherapy for cancer raises a number of safety issues, related to the toxicity of the drugs used and the need for specialized training to administer the treatment. On contact, chemotherapy drugs can cause potentially severe local tissue necrosis; many of these agents have shown fetotoxicity, mutagenicity, teratogenicity, and carcinogenicity in experimental animals and humans [Grajny et al., 1993]. Degree of risk varies for different agents. Safe treatment delivery depends on:

- close monitoring of the patient, to watch for critical adverse reactions, particularly extravasation of vesicant drugs, dehydration, bone marrow suppression, and anaphylactic drug reactions [Parker, 1992]. When monitoring is especially crucial or when the patient is receiving his/her first treatment cycle, therapy is usually administered in the hospital setting instead;
- ability of the patient and/or informal caregiver(s) to be successfully trained. If not actually administering the drug, this person may still be involved in monitoring of side effects and/or clean up and disposal of waste;

- suitability of the home environment. Reliable plumbing, electricity, and telephone service are required;
- specialized equipment being brought to and readily available in the home, including a spill kit (containing emergency medications, surgical latex gloves, a disposable gown, splash goggles, a respirator mask, absorbent material, spill control pillows, puncture-proof containers, plastic disposal bags, scoop/brush to collect glass, and toxic waste labels) [Parker, 1992].

As a result, some patients are likely to be ineligible for home chemotherapy: besides those receiving their first chemotherapy cycle, other patients likely to be excluded include those who (1) have experienced a previous anaphylactic reaction to the drug, (2) need to receive a drug which is not appropriate for home delivery (due to the nature of the drug and/or its administration), (3) are known to be non-compliant with medical treatment, (4) are unable to understand treatment instructions or are severely physically disabled, or (5) have multiple chronic and unstable health problems [Parker, 1992]. Young children may have to be kept away from the patient during drug administration [Parker, 1992].

The technical and safety training required for patients and caregivers can include the following [Catania, 1999; Dougherty et al., 1998; Aiello, 1996; Gorski and Grothman, 1996; Lowdermilk, 1995; Parker, 1992]:

- for intravenous delivery, catheter care (e.g. flushing), central line dressing change, and pump operation and maintenance;
- management of side effects and complications; in this respect, chemotherapy at home does not differ substantially from the outpatient setting since in the latter case side effects are also likely to develop while the patient is at home (after returning from the clinic);
- self-care related to living with infusion pumps (e.g. managing pump checks and alarms, and dressing and bathing);
- special monitoring of vesicant drug delivery;
- handling of patient excretions (urine, stool, vomit, and blood may contain the drug for up to 72 hours after administration);
- drug administration precautions and procedures (e.g. drawing up and adding intravenous medications);
- aseptic techniques (e.g. hand-washing, sterile gloving);
- handling and disposal of items that were in contact with the drug at the end of treatment;
- emergency responses and use of spill kits (e.g. reacting to symptoms, alarms, and technical errors).

According to literature published in the US, chemotherapy drugs are usually delivered to the home premixed in the IV bag/reservoir with preprimed tubing; disposal containers are also often provided and picked up by a pharmacy for disposal [Gorski and Grothman, 1996; Grajny et al., 1993]. Intravenous chemotherapy drugs are normally prepared at a centralized production facility. Pharmacists need to be informed of the conditions in which the drugs will be used, since these affect their chemical stability and compatibility; for instance, in ambulatory infusion the drugs will often be exposed to higher temperatures close to the patient's skin [Beijnen, 1992]. Although a portable ambulatory pump is a closed system, spill potential still exists and patients need to have spill kits with them when carrying out their activities [Ryan, 1996].

To deal with these safety issues, there is a need for standard nursing/pharmacy protocols and policies to be in place regarding patient selection, chemotherapy administration and other care in the home setting, technical training of informal caregivers, and transportation and safe storage of drugs. All equipment, human waste, and unused drugs should be considered as chemically hazardous waste, and dealt with according to medical facility standards [Mayer, 1992]. Guidelines on proper handling during all steps of chemotherapy preparation and delivery have been developed by the Occupational Safety and Health Administration (USA), the Oncology Nursing Society (USA, in 1996), the US

National Study Commission on Cytotoxic Exposure [Parker, 1992], the American Society of Clinical Oncology (USA, in 1996), and the American Society of Hospital Pharmacists, among others, to protect patients, their families, and their care providers [Grajny et al., 1993; Mayer, 1992].

In Canada, provincial guidelines have been developed by cancer agencies and associations based on directives by Health and Welfare Canada and adaptations of American guidelines. In Québec, the *Regroupement des pharmaciens en oncologie* has developed an extensive guide to cancer chemotherapy delivery, which includes material on extravasation, properties of the principal agents used, information for patients on chemotherapy drugs and supportive medications, technical directives (regarding preparation, medical surveillance, drug administration, safety issues, and emergency procedures) and chemotherapy in the home setting [Regroupement des pharmaciens en oncologie, 2001]. The first section on home chemotherapy is intended as a general tool to aid pharmacists in choosing an appropriate device for drug delivery, with detailed information on the equipment most frequently used in Québec. The protocols that can potentially be administered at home are described as well as general patient eligibility criteria and patient/caregiver training.

Oral chemotherapy at home also has important safety implications, because the health care professional can have less control over the specific dose ingested by the patient (when compared to nurse-prepared infusions, for example). Patient education on the correct oral dose schedule, the recognition of potentially serious side effects, and deciding when to withhold treatment is thus crucial [Hollywood and Semple, 2001].

In the following section, we defined "safety" outcomes as the frequency and/or severity of medical complications, problems with devices, and toxicity (i.e., side effects).

3.3.2 Evidence regarding safety compared to institutional treatment

3.3.2.1 RANDOMIZED CONTROLLED TRIALS

In an American trial of home (Infusor® device) versus hospital (standard pump or Infusor) chemotherapy with 19 crossover patients who completed two or more cycles[5] (mean age 56 years), no device malfunctions occurred during the first two cycles nor in subsequent Infusor treatments [Vokes et al., 1989]. Five patients experienced non-life threatening complications in hospital related to the standard pump (including deep vein thrombosis, thrombocytopenia, a clotted device, and local infection; the device was removed from four patients). The home care group had to report daily to the clinic for blood testing during their first "outpatient" cycle (thereafter, they visited the clinic weekly). There were no significant differences in frequency or severity of side effects in the two settings, which included mild to moderate myelosuppression, moderate to severe mucositis, and two cases of neutropenic fever. One patient died during home treatment; the likely cause of death was thought to be cardiac arrhythmia related to specific risk factors associated with head and neck cancer.

In an Australian trial with 20 crossover patients (mean age about 60 years), no significant complications occurred following nurse-administered chemotherapy in the home setting[6] [Rischin et al., 2000]. Borras and colleagues found similar treatment toxicity in their home (n=45) and outpatient (n=42) colorectal cancer groups who both received nurse-delivered chemotherapy (5-FU for 5 days) in their RCT in Spain (mean age about 60 years) [Borras et al., 2001]. It should be pointed out that Borras and colleagues encountered high rates of withdrawal from each study group due to disease progression, unacceptable toxicity, or patient non-compliance, although this proportion was lower in the home group (27% vs. 45% for outpatients; overall, 1 in 3 study patients did not complete treatment). The difference in withdrawal rates

5 Five days of continuous 5-fluorouracil (5-FU) following methotrexate and cisplatin

6 Regimens included use of cyclophosphamide, methotrexate, 5-FU, doxorubicin, and vincristine

was due to significantly lower voluntary dropout among those receiving care at home (2 vs 14%).

In a European multi-site trial of 31 evaluable crossover patients (median age about 59 years), no significant (WHO grade III or IV) toxicity occurred while receiving daily oral UFT and leucovorin (3 times/day for 28 days every 5 weeks) [Borner et al., 2002]. UFT is a recent oral fluoropyrimidine formulation that combines uracil and tegafur. In comparison, daily bolus of 5-FU plus leucovorin administered at a facility (for 5 days every 4 weeks) was associated with a greater frequency of stomatitis and hematological toxicity (leukopenia, neutropenia). Mild side effects, including nausea, vomiting, and diarrhea, were similar in frequency under the two regimens. Of the original 37 previously-untreated patients with metastatic colorectal cancer who were randomized, one was ineligible due to advanced disease and 5 patients discontinued treatment early, due to diagnoses of brain metastases (n=1), non-measurable disease (n=1), and toxicity (n=3; little information is provided, but at most one of these had started with oral UFT).

3.3.2.2 CONTROLLED STUDIES

In Lowenthal and colleagues' study of Australian cancer patients who received hospital day ward (n=119) or home chemotherapy (n=65; the latter including workplace, GP office, and day care centre locations, where treatment was delivered by nurses for 15 minutes to 3 hours), serious complications in the home setting were rare: only one dystonic drug reaction occurred, requiring hospital treatment but not admission (no demographic data provided)[7] [Lowenthal et al., 1996]. Minor difficulties with venous access at home were infrequent.

In a retrospective American study of 152 adult patients (mean age 62 years; almost entirely male) who had venous access devices surgically implanted at one medical centre, 32 patients received infusion chemotherapy exclusively at home while others received either strictly institution-based therapy or were treated in both settings (numbers of patients in these groups not specified)[8] [Brown et al., 1997]. A total of 27 patients (18% of 152) had one complication each, which was not significantly associated with their age, port access frequency, tumour type, or presence of neutropenia. All chemotherapy was started and ended by oncology nurses at the hospital clinic. There was no difference in complication rate between those who received only home-based versus only hospital-based treatment (23% versus 24%, respectively). Of the 17 ports removed due to complications (sepsis: 10, fever of unknown origin: 2, subclavian vein thrombosis: 2, mechanical failure: 1), 3 of these were among the 32 patients who were treated exclusively at home.

A study in Israel with advanced colorectal adenocarcinoma patients (mean age about 68 years) showed lower toxicity in the home care group, which was actually composed of those with more advanced disease: 46% of the home care (n=35; oral ftorafur) and 27% of the hospital care groups (n=26; intravenous 5-FU) had no side effects from the treatment (p value calculated by authors of the present assessment report not significant) [Ron et al., 1996]. Nurses visited the home care patients biweekly for blood testing. Gastrointestinal side effects were the most frequent in both groups, but occurred with greater severity among those receiving intravenous infusions in hospital/clinic (5-FU is known to have greater toxicity).

A study of 15 women with gynecologic cancer in USA examined a total of 74 cisplatin combination treatment courses[9] given at home, following an initial course in hospital (as inpatients) and under the direction of a chemotherapy nurse [Malone et al., 1986]. No anaphylactic reactions or extravasations occurred, nor was it necessary for any patients to be hospitalized for adverse reactions following treatment delivery at home.

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7 Chemotherapy protocols included use of cyclophosphamide, methotrexate, 5-FU, doxorubicin, vincristine, mitozantrone, interferon, vinblastine, and epirubicin.

8 Regimens included use of carboplatin/cisplatin, high-dose methotrexate, 5-FU, and doxorubicin.

9 In addition to use of cisplatin, cyclophosphamide, and doxorubicin, one patient received continuous bleomycin sulphate over 48 hours by pump.

3.3.2.3 Uncontrolled studies

A prospective German study of 35 adults who self-administered subcutaneous chemotherapy (interleukin-2 and interferon-α 2b) for progressive cancer at home (median age 55 years) showed no need for inpatient treatment and no treatment-related deaths [Atzpodien et al., 1990]. Toxicity was moderate, with WHO grade I and II adverse effects (fevers, chills, anorexia, nausea, and hypotension), and dose was reduced for six patients. Blood counts were carried out weekly. Four patients (11.4%) did not fully comply with the treatment regimen, which required abdominal injections every 12 hours for a total of 7 days during each cycle.

In an American study of stage IV recurrent or metastatic breast cancer patients, 16 women (median age 54 years) were treated with 2-week cycles of a 1-hour infusion of paclitaxel as outpatients followed by two 4-day periods of continuous 5-FU using central venous catheters and portable pumps at home [Collichio et al., 2002]. Toxicity was mild, with no grade III or IV hematologic toxicity and mostly grade 0 or I level diarrhea, fatigue, nausea/vomiting, mucositis, peripheral neurotoxicity, and hypersensitivity (except for one grade IV reaction to paclitaxel). Four patients (25%) had problems with their pumps which disrupted their treatment at home (one pump stopped, one ran without medication, and two were insufficiently large for the required volume). It should be noted that at the beginning of the study, 5 patients were started on higher dose paclitaxel which was associated with excessive toxicity.

Among 50 Italian patients with ovarian cancer (median age 47 years) who self-administered oral melphalan (PAM) chemotherapy (300-650 mg over 5 consecutive days after checking blood counts) for at least 6 months, one patient accidentally took too high a dose (950 mg cumulatively) [Spatti et al., 1987]. Another patient was lost to follow-up, and 6 patients died. Among 43 patients evaluable for toxicity (outpatient follow-up every 3-4 months), no cases of acute nonlymphocytic leukemia occurred, a risk which has been identified with doses of 700 mg or more; at the time of reporting, the patient with the overdose was not affected after 16 months of follow-up. Sixty-five percent of patients had myelodepression, while leukopenia affected 58% and thrombocytopenia occurred in 28% (the latter two mostly of mild severity). Fifteen patients (35%) did not experience any hematologic toxicity.

A second Italian study of 43 elderly colorectal cancer patients (median age 74 years) also examined self-administration of oral chemotherapy (doxifluridine) at home, for a median duration of 9 weeks [Falcone et al., 1994]. This therapy was well tolerated among the 42 patients who received treatment; common side effects included nausea and vomiting (for 29% of patients), diarrhea (21%; severe for 17%), stomatitis (7%), and leukopenia (7%), which resulted in stopping treatment for three patients. Doses were reduced from 2250 mg/day to 1500 mg/day for 15 patients (36%). There were no cases of neurotoxicity, cardiotoxicity or toxic deaths.

Benahmed and collaborators studied 23 patients with metastatic tumours (no age data provided) who received continuous intravenous infusions of cisplatin at home using balloon infusors, over 4 successive days every 4 weeks in France [Benahmed et al., 1986]. Each patient received at least one treatment cycle over a 6-month period (range: 1-5 cycles) with either central subclavian (n=7) or peripheral arm catheters (n=16). Supervision was provided through a mini personal computer with telephone access, and the pumps were distributed daily by the hospital pharmacy. Pump reliability and treatment tolerance were checked 'regularly' by nurses at the beginning and end of each perfusion (no other details on this surveillance were given). Oral hydration and anti-emetic therapy were started in hospital prior to each cycle and a clinical patient evaluation was completed before and 24 hours after each treatment. A total of 185 infusors were used for 16 to 31 hours each (average: 23 hours). There were no cases of major irreversible toxicity. Twenty-two percent of patients experienced minor nausea and vomiting. One patient developed functional renal insufficiency that was easily reversible with hydration. Seventy-five percent of the 16 patients with peripheral catheters developed phlebitis (treatable with intravenous

hydrocortisone). Two patients with peripheral access (12.5% of 16) experienced perivenous edema in the arm due to gradual extravasation of cisplatin. No neurological side effects were observed.

Greidanus and colleagues reported on 50 adult patients (mean age 51 years) who received 3-week infusions of chemotherapy at home using totally implantable venous access ports and portable pumps in the Netherlands [Greidanus et al., 1987]. Patients were trained by nurses to dissolve and mix their own drugs (4-epidoxorubicin or mitoxantrone) and fill the syringe with the correct fluid amount every 48 hours at home, as well as handle the infusion pump (worn in a shoulder holster). They were seen weekly in the outpatient clinic, where they received one week's worth of drugs and dilutant, and could access a physician by telephone 24 hours/day. Three initial study participants chose not to take on the care responsibilities and left the study.

A total of 114 cycles of chemotherapy were administered to the 50 patients, who received from 1-9 cycles each over 2,394 infusion days. Seven complications due to the port occurred (in 6.1% of cycles), and included 2 venous thrombosis events (therapy could not continue for one patient), 1 pulmonary embolism (therapy continued after anti-coagulant treatment), 2 needle dislocations leading to drug extravasation without skin necrosis (therapy interrupted for less than 1 week), 1 temporary catheter occlusion, and 1 case of cellulitis which responded well to antibiotics. There were 9 temporary pump arrests (7.9% of cycles) for a maximum of 24 hours, mostly due to incorrect syringe placement, and no pump failures for mechanical reasons. There were 5 problems with the needle-extension tube connection (4.4% of cycles). Despite patients dissolving their own drugs and connecting the filled syringes there were no cases of septicaemia.

Nanninga and collaborators combined the results of eight phase I and II studies, in which intravenous access devices and portable pumps were used to deliver home chemotherapy to Dutch patients seen in their outpatient department [Nanninga et al., 1991]. This 1991 study included some of the patients examined by Greidanus and colleagues [Greidanus et al., 1987], and similar services were provided. In seven of the studies patients learned how to prepare their drugs (as described above); in one study, pre-filled syringes were delivered to the home by the hospital pharmacy. All patients were taught how to manage and change syringes. One hundred and seventy patients with a variety of cancer diagnoses (mean age 52 years) received 3-week infusions of epirubicin (n=70), mitoxantrone (n=35), carboplatin (n=44), or 5-fluorouracil (n=21; 2-week infusions), for a total of 440 cycles and 8,437 infusion days. Most complications were easily managed. There were 10 cases of venous thrombosis; for five of these patients, treatment had to be stopped (two study patients did not complete an entire treatment cycle as a result). Two patients developed a pulmonary embolism (one of these had a venous thrombosis). There were 20 catheter occlusions (usually flushed with no treatment delay), 6 dislodged needles (causing extravasation but no necrosis or infection), 3 local skin infections, 10 pump failures (mechanical problems or incorrect syringe placement), and 20 external catheter fractures due to bending. One systemic infection occurred, which responded well to antibiotics.

In a German study of cancer home care, treatment at home was offered to 102 patients in 14-month period and was chosen by 99 persons (no demographic data provided) [Ophof et al., 1989]. Forty-six patients received continuous chemotherapy via an implanted port and portable pump (27 intravenous and 19 hepatic-artery infusions), which represented 220 treatment cycles and 1,113 days of home treatment (drugs not specified). Fifteen other home cancer patients had nutritional support, 25 were recovering from surgical procedures, and 13 received supportive terminal care. A mobile home care team set up by a surgical oncology unit (and composed of two nurses, two physicians, and one psychologist) acted as a link between the hospital, general practitioners, community nurses, and patients. This team organized discharges to the home, coordinated services, trained patients and/or family members, managed patient follow-up, and provided psychological support to the patients and their families. Details on treatment supervision were not provided in the study article.

In the 1,113 days of home chemotherapy there were 24 cases of extravasation (2.2% of treatment days and 10.9% of cycles) and 2 catheter thrombosis events (less than 1% of both treatment days and cycles). Delays in infusion course, needle dislocations, and emergencies due to technical problems were noted as 'rare'. Thirty of the 99 home patients required 709 in-hospital days due to changes to or extensions of their therapy. Complications during home care required 189 in-hospital days (number and types of patients not specified). Six of the 99 cancer patients were readmitted to hospital because their families could no longer cope with home care.

We identified a number of uncontrolled studies that provide information on safety of home chemotherapy for children. Lange and colleagues report on home methotrexate infusions for 22 American children and young adults (aged 2 to 20 years) with ALL [Lange et al., 1988]. There were actually 27 patients in their program; five of these were not able to receive home therapy due to working parents or inappropriate home environments, prior complications (neurotoxicity, venous access problems, and hepatic fibrosis), and refusal to participate in one case where the child enjoyed the hospitalization. Following the first course of therapy in hospital, subsequent infusions were started by home care agency nurses at the hospital outpatient clinic (after medical evaluation) and then continued at home in the presence of one parent or other trained adult; home care nurses also provided 24-hour telephone support. Nursing home visits occurred when necessary, and were particularly important for those families residing farther away, where local nurses assisted with administering treatment.

The most common complication in this study was subcutaneous infiltration of the peripheral intravenous lines (six patients; 27%); two of these required hospital admission to re-start the infusion (and two children subsequently received central venous access catheters). In two cases there was miscommunication during the parental training which caused anxiety and required intervention by the oncologist. One infusion pump had a mechanical failure, interrupting an infusion; subsequently, a back-up pump was always made available in the homes. One nurse resigned from duty and could not be replaced locally.

A second American study of 20 children with various cancers including ALL (aged 2-18 years) also provided infusion treatment training to parents[10] [Jayabose et al., 1992]. The patients had previously tolerated infusion chemotherapy in hospital without severe vomiting, and 19/20 had a central venous catheter; one had an implantable venous access port. While all patients were eligible for home slow intravenous push chemotherapy (IVP), three were not eligible for home intravenous infusion with a pump (IVI, which requires more skill and training to administer) due to inappropriate home situations. Nurses supervised the parents (who delivered the chemotherapy) when necessary. For the 435 doses of chemotherapy received at home (343 IVP; 92 IVI), no immediate adverse effects were observed.

Holdsworth and colleagues studied 44 consecutive American patients (aged 1 to 19 years) with various cancers who received 262 courses of chemotherapy[11] [Holdsworth et al., 1997]. Nurses from local private home care agencies delivered all treatments at home (and were available for emergency visits 24 hours/day, 7 days/week), while the parents were trained to recognize problems. Many of the patients had received their first treatment cycle in hospital and none had experienced a previous adverse reaction to medications. There were no acute complications that required hospital admission in the home setting. Based on a survey of 16 patients on the day after each home chemotherapy treatment ended (N=66 courses of highly emetogenic therapy), nausea/vomiting control (kept to zero or mild) was obtained with anti-emetics (ondansetron and methylprednisolone) for approximately 80% of respondents. Although one of the anti-emetics used at home was not often

10. Chemotherapy regimens included use of cyclophosphamide, methotrexate, vincristine, dactinomycin, etoposide (24-hr infusion x 4 days), and cytosine arabinoside (the last at high dose combined with etoposide for 2 patients).

11. The most frequently administered regimens involved (1) vincristine, cyclophosphamide, dactinomycin, (2) ifosfamide (for 3 or 5 days), etoposide, and (3) high-dose methotrexate.

previously available, comparative data for 19 patients who received 51 prior chemotherapy courses in hospital show nausea/vomiting control for about 63% of patients. This percentage increases to 79% for nausea and 68% for vomiting when the analysis is limited to the 19 prior courses of ondansetron and methylprednisolone in hospital.

A UK study of central line intravenous therapy delivered by parents to their children with cancer included 89 courses of antibiotics, chemotherapy, or anti-emetics over a 1-year period (totalling 469 home treatment days; no age data) [Hooker and Kohler, 1999]. Ongoing home support was provided by pediatric community nursing teams. Ten patients received intravenous bolus low-dose chemotherapy (cytosine arabinoside) over 129 treatment days; no problems were experienced. Twenty-three children were treated with antibiotics at home for a median of 4 days following early discharge from hospital, regardless of neutrophil count, and four of these required re-admission due to fever, continued pain, or parental concern (all recovered without event). Another 12 antibiotic patients were managed entirely at home with a median treatment duration of 5 days; one of these was re-admitted for exit site infection and a second child with persistent symptoms had a second antibiotic added to the home treatment. Of the seven patients receiving anti-emetics at home, two required treatment adjustment before resuming home care (one of these required a day admission in hospital for symptom control). Hooker and Kohler state that the hospital admissions and treatment adjustments required by the children in this study were typical of the patient group, and were not considered to be related to the home therapy setting.

Lastly, we also located an older report on a home intravenous chemotherapy service that began in Pennsylvania, USA in 1975 [De Moss, 1980]. By the time the article was written, visiting nurses had provided over 400 home treatments to more than 70 patients[12] (aged 29-90 years; therapy provided from weekly to once every 6 weeks). Minimal side effects were observed: very infrequent bleeding caused by thrombocytopenia, leukopenia requiring hospital isolation (n=1), mild rectal bleeding (n=2), severe mucositis requiring treatment discontinuation (n=1), intractable vomiting (n=1; thought to be due to gastric metastasis), and vein hyperpigmentation (n=1). Bone marrow depression was experienced in varying degrees by most clients, but is considered a common result of most chemotherapy drugs. No cases of drug extravasation occurred. Most significantly, nausea and vomiting were remarkably uncommon, despite the fact that some clients had experienced severe symptoms during chemotherapy in a clinic or doctor's office; the absence of symptoms could not be explained by dose alterations.

3.3.2.4 Conclusions

Table 3 summarizes the studies that include information on safety and toxicity, with respect to the severity of complications and other findings. Although it should be kept in mind that rare adverse reactions may not be evident in small samples, it appears that home chemotherapy can be provided safely [Holdsworth et al., 1997]. This is perhaps not entirely surprising given the strict selection criteria generally used to deem patient eligibility in these investigations. For 5 of the 10 adult studies with treatment supervision details and which involved intravenous therapy (assuming this to be the method presenting the most risk), either a nurse administered the treatment or daily nursing home visits were provided [Borras et al., 2001; Rischin and Matthews, 2001; Lowenthal et al., 1996; Malone et al., 1986; DeMoss, 1980].

12. Drugs administered included cyclophosphamide, methotrexate, 5-FU, doxorubicin, vincristine, bleomycin, mithramycin, and thiotepa.

TABLE 3

Summary of studies examining safety and toxicity

STUDY / TYPE OF THERAPY AT HOME; N*	LESS SEVERE COMPLICATIONS AT HOME	MORE SEVERE COMPLICATIONS AT HOME	OTHER FINDINGS
RCTs			
Vokes et al., 1989 / intravenous; N=19	5 non-life threatening complications due to pump	1 death due to arrhythmia	No device malfunctions No significant differences† in side effect frequency/severity
Rischin et al., 2000 / intravenous; N=20		No significant complications	
Borras et al., 2001 / intravenous; N=45 vs 42			No significant differences† in toxicity
Borner et al., 2002 / oral; N=31	32% nausea, diarrhea; 23% vomiting (all mild)	No WHO grade III or IV toxicity	4 times less stomatitis and hematological toxicity than iv method
Controlled studies			
Lowenthal et al., 1996 / intravenous; N=65 vs 119	Infrequent minor venous access difficulties	1 serious complication requiring hospital treatment, no admission	
Brown et al., 1997 / intravenous; N=152	18% had 1 complication 3/32 home ports removed		No significant differences† in complication rate
Ron et al., 1996 / oral; N=26 vs 35			Lower toxicity in home care group
Malone et al., 1986 / intravenous; N=15 (crossover)		No anaphylactic reactions or extravasations	No adverse reactions requiring hospitalization
Uncontrolled studies			
Atzpodien et al., 1990 / injection; N=35		No treatment-related deaths or hospitalizations	Dose reduced for 6 patients Moderate toxicity (grade I, II)
Collichio et al., 2002 / intravenous; N=16	Mostly mild toxicity only 25% pump problems	1 hypersensitivity reaction No deaths	1 each of grade III mucositis, fatigue, diarrhea
Spatti et al., 1987 / oral; N=43	Mostly mild leukopenia and thrombocytopenia	1 accidental overdose	65% myelodepression; no acute non-lymphocytic leukemia
Falcone et al., 1994 / oral; N=42	36% required dose reduction	No neuro- or cardiotoxicity No toxic deaths 17% severe diarrhea	n=3 (7%) treatment stopped due to toxicity (mostly diarrhea)
Benahmed et al., 1986 / intravenous; N=23	22% mild nausea, vomiting Phlebitis in 12 of 16 with peripheral access (treated)	1 renal insufficiency case (easily corrected) 2 perivenous edema due to gradual extravasation	No major irreversible toxicity No neurological side effects

Summary of studies examining safety and toxicity (continued)

STUDY / TYPE OF THERAPY AT HOME; N*	LESS SEVERE COMPLICATIONS AT HOME	MORE SEVERE COMPLICATIONS AT HOME	OTHER FINDINGS
Uncontrolled studies (continued)			
Greidanus et al., 1987 / intravenous; N=50	7 port, 9 pump & 5 tube/ needle complications (6.1, 7.9, & 4.4% of cycles) 2 extravasations, no necrosis (therapy continued)	1 pulmonary embolism (therapy could continue) 2 venous embolisms: therapy discontinued for 1 1 treatable cellulitis	No septicaemia occurred 1 catheter had to be removed (therapy discontinued) Max pump arrest time 24 h No mechanical pump failures
Nanninga et al., 1991 / intravenous; N=170	6 needle dislocations & 20 catheter occlusions (1.4 & 4.5% of cycles) 3 local infections	2 pulmonary embolisms 10 venous thrombi (5.9% of patients; discontinued therapy for 5)	1 treatable systemic infection 10 pump failures & 20 tube fractures due to bending (2.3 & 4.5% of cycles)
Ophof et al., 1989 / intravenous; N=46	Brief therapy delays, needle dislocations, technical emergencies rare	2 catheter thrombosis events (<1% of cycles and treatment days)	24 extravasations (10.9% of cycles, 2.2% of treatment days)
Lange et al., 1988 / intravenous; N=22 PEDIATRIC	1 pump mechanical failure	27% had subcutaneous infiltration (2 admitted)	2 cases of miscommunication causing anxiety
Jayabose et al., 1992 / intravenous; N=20 PEDIATRIC			No immediate adverse effects
Holdsworth et al., 1997 / intravenous; N=44 PEDIATRIC	80% nausea/vomiting control	No acute complications requiring hospitalization	
Hooker and Kohler, 1999 / intravenous; N=10 PEDIATRIC			No problems; typical hospital admissions/dose adjustments
DeMoss, 1980 / intravenous; N>70	2 mild rectal bleed 1 vein hyperpigmentation Infrequent bleeding due to thrombocytopenia	1 leukopenia (admitted) 1 severe mucositis (treatment discontinued) No extravasations	1 intractable vomiting due to gastric disease Bone marrow depression in most patients, but expected

*When "vs" is specified, second group listed contains controls

†When compared to non-home care control group

3.4 PSYCHOSOCIAL ASPECTS

3.4.1 Psychosocial issues involved in the choice of home or institutional chemotherapy

Assessment of the patient's experience with home chemotherapy is a crucial aspect of an evaluation of this treatment delivery setting. Table 4 presents a number of possible advantages and disadvantages of home chemotherapy (if eligible for this choice), from the perspective of both patients and their caregivers at home.

The relevant psychosocial issues could differ according to the age and family role of the patient. In the case of children, the hospital setting may be particularly foreign and frightening. For adults, if the patient had more homemaking or childcare responsibilities prior to his/her illness, being at home for treatment may lead to more pressure (being exerted by him/herself or others) to continue this role in a manner which is unreasonable given his/her physical state.

Another important factor to keep in mind is the possible 'transformation' of the home and patient related to the cancer illness, as put forth by Ruddick [Ruddick, 1995]. Patients with cancer may discover that home is a less comforting (or comfortable) place than originally expected, when faced with changes brought on by the illness and the requirements of home treatment. For example, kitchen noises/odours and noises in general may be disturbing, physical alterations in the home may be disorienting (e.g. rented hospital beds, drawn curtains, other equipment), and unlocked or open bedroom doors threaten privacy. The impact of the illness and treatment on family relationships should also be considered. Caring family relationships can be transformed into difficult interactions where patients' complaints and sufferings are constrained, 'visiting hours' are essentially continuous, caregivers develop resentment, and regressive patient behaviour is promoted by a lack of social stimulus. In cases where institutional settings can be made more 'homelike' (through the use of innovative design and interior decorating), are accessible by the patient (i.e. do not require lengthy travel time), and where care is handled by professional caretakers instead of intimates, it may be preferable for a patient to return to his/her home once treatment is completed.

To add to this discussion of psychosocial issues, we looked at patients' perspectives on the experience of chemotherapy in general, in the hospital or clinic setting. As discussed in section 1.3.2, chemotherapy is usually associated with a number of distressing physical side effects for the patient, in addition to the emotional trauma brought about by the cancer diagnosis. These difficulties are handled by individual patients to different degrees. A UK qualitative study by Colbourne looked at patients' views on the chemotherapy treatment experience through interviews with 24 adult patients with testicular or ovarian cancer [Colbourne, 1995]. A variety of chemotherapy regimens were prescribed and all patients had completed at least one course of treatment before participating in the study.

Symptoms that were reported to be the most difficult to cope with included hair loss, vomiting, nausea, disturbed sleep, loss in sexual feeling (for males), constipation (for males), malaise (for males), and reduced appetite (for females). Negative social aspects that were particularly endorsed by both genders were a reduction in social life and distress caused by waiting for treatment (clinic waiting times were 4-6 hours). Males also endorsed interference with daily activities (particularly inability to go to work) and distress associated with having to go to the hospital for treatment. Most study participants had experienced feelings of depression and disruption of activities due to side effects of therapy. About 50% reported feeling isolated, being anxious about needles, feeling depressed due to the time spent in hospital, having fear of the unknown, and finding their usual routine too demanding. While a few found it difficult to receive chemotherapy alongside others with cancer, the majority reported gaining support from other patients. One participant commented that control was lost when in the hospital, and that any level of symptoms was tolerable when experienced at home.

TABLE 4

Advantages and disadvantages in choosing home chemotherapy

ADVANTAGES	DISADVANTAGES
Convenience and comfort of reduced travel and waiting time, and fewer travel expenses	Commitment of much (unpaid) time to patient treatment/ supervision by informal caregiver(s)
More personalized treatment in a familiar surrounding, closer to family/friends	Increased anxiety for patient associated with being away from the security of the hospital environment and the ready accessibility of staff
Less disruption of routine and family life, and greater ability for patient to fulfil work and home responsibilities	No "escape" from the illness/treatment for others in the home; potential for negative (stress/anxiety) effects on patient's children
More involvement of family members in patient's treatment	Increased stress and fear in family members due to treatment responsibilities; informal caregivers have to be motivated/willing to help
More active treatment role for patient, reducing feelings of helplessness/vulnerability and increasing sense of control/independence	Decreased opportunity to share experience with other patients in hospital setting
Stable patients unlikely to receive as much attention from staff while hospitalized	Detachment from direct contact with primary physician and staff
Reduced exposure to hospital infections Greater possibility of receiving continuous long-term infusions (increased efficacy/ decreased toxicity)	Increased treatment time compared to in-hospital regimens; negative body image and increased discomfort resulting from long-term central venous access/infusion pump

Sources: Pfister, 1995; Dougherty et al., 1998; King et al., 2000.

Griffin and colleagues interviewed 155 cancer patients (median age 49 years; 76% female) who had received chemotherapy in the prior 4 weeks as outpatients or inpatients at an urban teaching hospital in Australia [Griffin et al., 1996]. Fifty-three percent of respondents were receiving chemotherapy for palliative reasons, 65% had metastatic disease, and 82% were given anti-emetics. Cancers included breast (45%), gynecological (22%), lung (7%), and other (26%). An average of 20 symptoms (65% of these physical) were reported by the study participants. The most severe symptoms were nausea, tiredness, and loss of hair. The most frequently endorsed psychosocial symptoms were dread of treatment, depression, anxiety, and being concerned about effects on family and on work/home responsibilities (reported by 50% or more of participants). Similar findings were recently reported in a study in France of 100 oncology outpatients (65% female; median age 58 years), where the most frequent cancers were breast (40%), gastro-intestinal (19%), ovarian (9%), and lung (7%) [Carelle et al., 2002]. Patients with advanced disease who had received chemotherapy as outpatients only in the prior month were interviewed. The most severe treatment effects were the impact on the patient's family/partner, hair loss, and fatigue, followed by impact on home/work responsibilities, social activities, and interest in sex.

An older study carried out in metropolitan Toronto (Ontario) looked at the impact of receiving chemotherapy through interviews with 67 cancer patients (average age 51 years; 90% female) [Todres and Wojtiuk, 1979]. Study participants had received chemotherapy for at least 12 months and 75% had breast cancer; 67% had metastases and prognosis was good for 39%. Twenty-eight percent of respondents had been able to continue working despite treatment side effects. In relation to their chemotherapy, 68% had experienced decreased strength, 53%

reported a greatly reduced ability to do household tasks, and 45% had become increasingly "moody". Negative effects on their sex life and on their relationship with the family after having chemotherapy were experienced by 28 and 22% of study participants, respectively.

Finally, we looked at a recent qualitative study by Richer and Ezer on the 'dimensions' of 10 Québec women's experiences with breast cancer [Richer and Ezer, 2002]. Study participants (mean age 56 years; from a variety of ethnic and socioeconomic backgrounds) were recruited at an outpatient clinic of a university hospital in Montréal and were receiving chemotherapy for the first time. The patients were interviewed several times over their remaining course of treatment (an average of 5.6 times per patient). The chemotherapy experience was described as a process that evolved over time and involved three dimensions: 'living in it' (an intra-personal aspect), 'living with it' (an inter-personal aspect), and 'moving on' (reconciliation of one's life). The women's need to "make sense of the world and their lives" [Richer and Ezer, 2002, p. 115] featured to different degrees throughout the treatment course, whereas coping with the immediate consequences of chemotherapy became less important as treatment was completed.

All participants experienced side effects that included fatigue, hair loss, gastric problems, altered taste, and reduced sexual activity. Most were astonished at how much side effects affected them. These side effects forced the women to face the reality of their altered situation. The women were alternately protective of their ill body 'as a friend' and frightened by their body letting them down 'as an enemy'. Mothers were especially worried about the family impact of their cancer and chemotherapy. Six of the 10 respondents found dealing with the perception of others was particularly difficult at the beginning of treatment (including dealing with too many questions and concerns of others). Most women reported difficulties with spending time in hospital and felt as though their lives revolved around oncology clinic visits (at least every 3 weeks). They felt overwhelmed by all the detailed information they had received about their treatments and managing side effects prior to therapy. In terms of coping, they tried not to focus too much on their disease and drew on support from families, friends, and communities. Getting to the end of the chemotherapy treatments was seen as necessary in order to proceed with their lives, get 'back to normal', and face the future.

3.4.2 Evidence regarding quality of life for cancer patients and their caregivers

We found a small number of studies in the scientific literature that specifically addressed patient quality of life (QOL) in home chemotherapy. King and collaborators examined quality of life according to the Functional Living Index—Cancer (FLIC) instrument, considering the global total as well as seven individual dimension scores (i.e., current health, role function, emotional function, hardship due to cancer, sociability, pain, and nausea) [King et al., 2000]. In addition to using the Karnofsky index to measure quality of life, Borras and colleagues used the EORTC QOL-C30 questionnaire, which includes five functional scales (physical, role, emotional, cognitive, and social), a global health status quality of life scale, and single measures of symptom severity (i.e. pain, nausea and vomiting, fatigue, dyspnea, constipation, diarrhea, appetite loss, insomnia, and financial difficulties) [Borras et al., 2001]. Neither group found any significant differences in quality of life in their randomized controlled trials of home chemotherapy. For Borras and colleagues, this result applied to measurements made at initial patient assessment, at completion of treatment, and to score changes during the trial.

In contrast, Close and collaborators showed that children with acute lymphoblastic leukemia had significantly higher quality of life during their home treatment (in a controlled crossover study; N=14), with respect to well-being ($p<0.001$), more independence and better appetite ($p<0.01$), and greater contentment and ability to keep up with school work ($p<0.05$) [Close et al., 1995]. Ability to sleep through the night and amount of time out of bed did not differ between treatment locations. The quality of life tool, specifically developed for the study using published assessment principles for pediatric cancer, was filled

out by both patients and their parents. Parents scored significantly higher on all four quality of life variables tested when treatment was at home: they were better able to keep up with household tasks and work responsibilities, and to spend time with each other and their other children at home ($p<0.001$).

We found three uncontrolled studies in the literature that used quality of life instruments to examine home chemotherapy. One of these simply reported that quality of life according to the FACT-B scale improved after 3 cycles of chemotherapy (the home component being two 4-day infusions of 5-FU), on the basis of mean scores from 14 interviews at baseline and 8 subsequent interviews [Collichio et al., 2002]. Of the eight women with metastatic breast cancer studied after three 2-week cycles, six experienced an improvement in QOL since baseline while two found QOL to be impaired. No further details on the role/impact of the home delivery setting were reported, but it was stated by the authors that the portable home pump was "cumbersome, occasionally inaccurate, and subject to mechanical problems" [Collichio et al., 2002, p. 197].

Hooker and Kohler sent postal questionnaires to parents after their child received home IV treatment, which included antibiotic therapy, chemotherapy, and infusion of anti-emetics (N of patients=35, 10, and 7, respectively) [Hooker and Kohler, 1999]. Parents rated their experience with respect to four quality of life variables. All parents felt that home therapy allowed for better management of housework and/or paid work, and more time could be spent with their spouse and other children (N=28; 86% response rate). Home treatment was perceived as less stressful than hospital therapy by 79% of respondents.

As a graduate dissertation at the University of Illinois, Hagle described the experiences of 53 cancer patients who had received continuous infusions by portable chemotherapy pumps at home (pumps were worn in a shoulder or waist holster) [Hagle, 1990]. Semi-structured interviews included the Quality of Life Index (QLI) and the Functional Living Index—Cancer (FLIC) instruments. The following information comes from the dissertation abstract. At the beginning of home treatment patients felt clumsy, awkward, and restricted when wearing the pump; at 3 months, most had gotten used to the pump but could not do as much as they had previously. Pumps caused the patients difficulties in getting dressed and wearing certain clothes. Half of the patients reported drastic changes to their bathing habits, and 38 patients reported problem episodes such as pump complications, tubing problems, and infections. The mean QLI and FLIC scores were, however, found to be high (the QLI tool consists of four subscales that address health/functioning, socioeconomic, psychological/spiritual, and family factors). No comparison data were provided in the abstract. Most patients reported liking the pump home therapy for its promotion of 'hope for life' and fewer side effects.

In conclusion, the evidence regarding quality of life for patients receiving home chemotherapy is limited by the small number of controlled studies and participants. The randomized controlled trials we identified in the scientific literature do not show a beneficial effect on quality of life; however, positive effects for both pediatric patients and their parents are supported by a controlled crossover study of home treatment for childhood cancer. Findings in uncontrolled studies are generally positive.

3.4.3 Evidence regarding patient preference for and satisfaction with home chemotherapy

Table 5 presents the findings of home chemotherapy studies which examined patient preference, satisfaction, and other psychosocial factors, such as independence, concerns, needs, level of stress, etc. All of the studies we found in the published literature have been previously described in this report with the exception of those by McCorkle and colleagues (Pennsylvania, USA) [McCorkle et al., 1994; McCorkle et al., 1989]. In the 1989 randomized study, 166 homebound lung cancer patients (between the ages of 18 and 89) received care (which could include chemotherapy) from oncology nurses, from an interdisciplinary health care team (including regis-

tered nurses and home health aides), or from their general practitioner [McCorkle et al., 1989]. Seventy-eight patients completed four interviews with psychosocial instruments (52% of recruits died during the study). In their controlled study of 138 patients with various solid tumours (median age 64 years), 49 home care and 11 'no home care' participants (43% of the original sample) completed two psychosocial interviews [McCorkle et al., 1994]. All patients lived within 50 km of a participating hospital; home patients received post-discharge nursing care during the time between the two interviews. (Although chemotherapy is not specifically mentioned, study patients had at least one 'complex nursing need' which could include dressing changes, colostomy, or nutritional support).

Table 5 includes data from an unpublished report that presented and evaluated a home chemotherapy program run since March 2000 by *Hôpital Maisonneuve-Rosemont*, a hospital affiliated with University of Montreal. The program won the *Concours Innovation clinique 2001* award from the provincial nursing association *(l'Ordre des infirmières et infirmiers du Québec)*. This study was the only completed evaluation we found among the Québec contacts we interviewed. Briefly, the program is offered through the outpatient department by a team that includes a full-time staff nurse, nurse-clinician, and pharmacist who can be contacted by the home patients (receiving continuous therapies with a balloon infusor) during office hours. Patients are seen at the outpatient department every 2 weeks to have a treatment cycle started; CLSC nurses disconnect the equipment at home or at a clinic. Outside office hours, patients can phone an oncologist if they have problems; they are also contacted at home by the program nurse the first day after treatment begins. Extensive nurse follow-up and patient training with both the nurse and pharmacist are provided. Local CLSC nurses (who automatically receive a patient information sheet) provide line management.

Of the 11 studies which reported on preferences and choice (marked with a P in Table 5), strong positive evidence favouring home treatment was observed in 9 of these [Borner et al., 2002; Remonnay et al., 2001; Rischin et al., 2000; Holdsworth et al., 1997; Close et al., 1995; Jayabose et al., 1992; Ophof et al., 1989; Lange et al., 1988; Malone et al., 1986]. In one of these 11 studies home therapy was only somewhat preferred (by 58%) [Vokes et al., 1989]. In terms of satisfaction (marked with an S in Table 5), 7 out of 9 relevant studies showed patients were satisfied with their home treatment, or at least some components thereof [Borras et al., 2001; Serrate et al., 2001; Hooker and Kohler, 1999; Lowenthal et al., 1996; Ophof et al., 1989; Lange et al., 1988; Malone et al., 1986]. However, two of the studies summarized in Table 5 showed results that did not favour the home setting: for King and collaborators, home and hospital were equally preferred when the analysis included all eligible patients in their RCT, and no significant differences were observed for satisfaction [King et al., 2000]. In an uncontrolled sample of 100 consecutive adult patients, Grusenmeyer and colleagues observed a high level of satisfaction with outpatient clinic care [Grusenmeyer et al., 1996].

TABLE 5

Summary of studies on patient and/or caregiver preference for and satisfaction with home chemotherapy

STUDY / TYPE OF THERAPY / OUTCOME	PATIENT POPULATION	STUDY DESIGN; N	RESULTS
RCTs			
Vokes et al., 1989 (USA) / iv / P	Adults, head & neck cancer, median age=56	RCT; N=22 crossover; at home or as outpat vs hospital	11/19 (58%) chose home treatment Reasons for declining: fear of malfunction, inconvenience of daily clinic visits, no supervision, restriction in home activities
McCorkle et al., 1989 (USA) / not specified	Adults, lung cancer, mean age~69	RCT; N=166 (2 home nursing groups vs GP care group) complete data: N=78	No sig differences in pain, concerns, or mood disturbance; home groups had sig less distress, independence for 6 weeks longer, worse health-over-time perception
Rischin et al., 2000 (Australia) / iv / P	Adults, various cancers, mean age~60	RCT; N=20 crossover	Home preferred subsequently by 100% 90% reported advantages: no travel, less burden/anxiety, able to continue duties
King et al., 2000 (Australia) / iv and oral / P, S	Adults, various cancers, no age data	RCT; N=40 crossover	73% of sample preferred home; of those eligible, home & hospital equally preferred No sig differences in satisfaction
Borras et al., 2001 (Spain) / iv / S	Adults, colorectal cancer, mean age~60	RCT; 45 home vs 42 outpat clinic	Sig greater satisfaction with some aspects of home nursing care (globally, not sig) Better treatment compliance at home
Remonnay et al., 2001 (France) / iv / P	Cancer patients (no other data)	RCT; N=42 crossover	95% preferred home setting
Borner et al., 2002 (Belgium, the Netherlands) / oral at home vs iv / P	Adults, colorectal cancer, median age~69	RCT; N=31 of 37 crossover; oral at home vs intravenous (at a facility)	84% preferred oral; before, concerns about side effects were the most important; after, mode of delivery was more important; iv preferred (n=5) due to injection modality and oral UFT-related toxicity
Controlled studies			
Malone et al., 1986 (USA) / iv / P, S	Adults, gynecologic cancer, no age data	Controlled; N=15 crossover	Patients preferred home mostly for familiar surroundings & personal care; concerns about hospital included inconvenience, increased anxiety & unsatisfactory facilities Home nurses evaluated favourably
McCorkle et al., 1994 (USA) / not specified	Adults, various cancers, median age=64	Controlled; 49 home vs 11 no home care	Sig improvement in mental health & social dependency at home; no sig differences in symptom distress or health perception
Close et al., 1995 (USA) / iv / P	Children, ALL, mean age=8.75	Controlled; N=14 crossover	13/14 (93%) subsequently chose home
Lowenthal et al., 1996 (Australia) / iv / S	Adults, various cancers, no age data	Controlled; 65 home vs 119 day ward	High rate of satisfaction: only 2/424 (0.5%) discontinued home care program
Serrate et al., 2001 (Canary Islands) / not specified / S	Adults, various cancers, mean age=76	Controlled; 10 home vs 10 out- and inpatients	Home patients satisfied with nurses' dedication and with 24 h telephone support by physicians

Summary of studies on patient and/or caregiver preference for and satisfaction with home chemotherapy *(continued)*

STUDY / TYPE OF THERAPY / OUTCOME	PATIENT POPULATION	STUDY DESIGN; N	RESULTS
Uncontrolled studies			
Grusenmeyer et al., 1996 (USA) / iv / S	Consecutive adult cancer patients (no other data) OUTPATIENT CLINIC	Uncontrolled; N=100	Patients highly satisfied with outpatient clinic care (median=98 on 100 mm VAS)
Ophof et al., 1989 (Germany) / iv / P, S	Adults, various cancers, no age data	Uncontrolled; N=46	97% (99/102) chose home care program Patients highly satisfied with medical treatment, care/support & program organization; home care avoided burden of hospital stay (46%), maintained family life (36%) and work/recreation activities (21%)
Lange et al., 1988 (USA) / iv / P, S	Children and young adults, ALL, 2-20 years	Uncontrolled; N=22	No family requested return to hospital treatment (first dose given in outpat clinic) Only one complaint, compared to frequent concerns from most families when in hosp
Jayabose et al., 1992 (USA) / iv / P	Children, various cancers, 2-18 years	Uncontrolled; N=20	No parents requested change to non-home care; home care viewed as less disruptive, saved time & allowed participation in care
Holdsworth et al., 1997 (USA) / iv / P	Children, various cancers, mean age=9.5	Uncontrolled; N=44	No patients withdrew or requested hospital admission for future treatments
Hooker and Kohler, 1999 (UK) / iv / S	Children, various cancers, no age data	Uncontrolled; N=10 chemo, 7 anti-emetics only, 35 antibiotics only; 28 parents	For the majority of parents, home therapy was not more stressful & they had enough home support, were better able to cope, learned more about the illness, and had more control over their child's care
Bélanger et al., 2001 (Québec, Canada) / iv / Unpublished study: *Programme d'administration continue de chimiothérapie à domicile*	Adults, various cancers, no age data	Uncontrolled; N=32 responded to self-administered questionnaire (out of 45 users in 10 months)	97% found information easy to understand, sufficient or helpful; 84% did not need nurse or pharmacist access for problems 87.5% felt confident at home 74% saw only advantages (thought less about their illness, more freedom, much less nausea, treatment more tolerable at home); 7 persons (22.5%) saw benefits as well as disadvantages (relating to risks if problems arise and less surveillance)

Abbreviations:
ALL=acute lymphoblastic leukemia; chemo=chemotherapy (intravenous); GP=general practitioner; hosp=hospital; iv=intravenous delivery; outpat=outpatient; P=preferences studied; S=satisfaction studied; sig=significant; VAS=visual analog scale.

It appears that an important factor in patient preference for and satisfaction with home chemotherapy is the selection effect: those patients offered the choice have already met somewhat stringent eligibility criteria, and participants in research studies on home treatment must consent to the possibility of having such therapy in order to be included. The trial by Borner and colleagues differs from the other controlled studies in that treatment modality was not the same in the home and institutional settings: after one cycle with each therapy type, oral UFT at home 3 times/day (for 28 days every 5 weeks) was preferred over bolus injections of 5-FU on 5 consecutive days (every 4 weeks) given at a facility [Borner et al., 2002]. Compliance with oral therapy was monitored through a patient diary and returned containers, and pharmacokinetic data were collected using plasma sampling. This study highlights the emerging importance of oral chemotherapy as new formulations are developed. If it is possible to choose between intravenous treatment delivered at a facility or oral therapy, the advantages of the latter include remaining at home, no need for potentially painful injections, avoidance of problems associated with venous access, and reduced costs of drug administration (no specialized equipment, less home monitoring, less nursing and pharmacy time) [Borner et al., 2001]. On the other hand, some patients prefer to delegate treatment responsibility to professional care providers and are concerned about their own medication compliance; also, oral therapies usually require extended, daily treatment periods, constantly reminding patients of their illness [Borner et al., 2002].

In a final part to section 3 we present two studies which examined factors that influence treatment preferences of cancer patients. Christopoulou specifically looked at the decision to be treated at home or in hospital, through interviews with 184 patients (in the mid-stage of their treatment) who were undergoing chemotherapy in Greece [Christopoulou, 1993]. The patients were identified at cancer hospitals and through the home care services of several hospitals. In multivariate analysis, the two factors significantly associated with the choice between home and hospital were whether the patient had experienced home care previously and the extent to which home care services were developed in their area. Employed patients preferred the convenience of home care, and most respondents believed home treatment satisfied all of their needs and those of their family. Economic variables did not seem to play a significant role in the choice, nor did sociodemographic factors (gender, family status, educational level).

Kiebert and colleagues had a different study objective: they examined the influence of seven different factors on a choice between two cancer treatment options differing in their expected outcomes on quality and length of life [Kiebert, 1994]. (Option A offered a good chance of cure but considerable side effects; option B offered a somewhat lower chance of cure but fewer side effects.) While chemotherapy at home was not considered in this study, the findings are of interest if one considers the possibility that patients perceive a different quality of life in the hospital versus home treatment settings.

With respect to the choice between options A and B, 199 Dutch patients between the ages of 18 and 75, with various kinds of cancer, were asked to indicate the relative importance of (1) age at time of decision; (2) having a partner; (3) having children; (4) inability to work due to side effects; (5) nature of side effects; (6) cancer-related life expectancy; and (7) quality of life before onset of cancer. The factor considered the least important for the choice between option A and B was the negative effects of the treatment option on ability to work, while the most important was chance of survival before treatment. The influence of having children was associated with marital status (most important for widowed persons, least important for single patients). The 'nature of side effects', 'life expectancy' and 'prior quality of life' factors were all associated with age, being more important for older patients. The authors concluded that cancer patients are willing to accept treatments associated with lower quality of life if there is a good chance of cure. When chances of survival are small, quality of life is likely to be favoured over length of remaining life.

4 INFORMATION FROM PROVIDERS ON CURRENT HOME CHEMOTHERAPY SERVICES

In this section, we describe home chemotherapy activity at several selected sites in Québec. During the time period of this assessment, it was difficult to find out where home chemotherapy was being offered in the province as there were no directories of oncology treatment services, comprehensive sources of utilization data, nor relevant publications; thus, we are not able to present an exhaustive survey of services across the province. We instead gathered information on a site-by-site basis in selected areas through interviews with contacts in several settings and regions. This information is intended to provide general perspectives on the benefits, barriers, facilitating factors, and challenges of home chemotherapy based on various programs.

The information presented in section 4.1 is based on semi-structured qualitative interviews with service providers/administrators from hospital and health system settings in Québec. In section 4.2, we make a comparison by presenting information about home chemotherapy activity in Ontario, a province with similar population size and geographic distribution (i.e., a concentration of people in a small number of urban centres and a widespread rural population). This comparison is especially useful given two essential organizational differences regarding cancer care in the two provinces: unlike Québec, Ontario has a provincial cancer services administrative body (Cancer Care Ontario) which finances a system of regional cancer centres connected to host hospitals and distributed throughout the province. The Ontario data are likewise based on semi-structured qualitative interviews with service providers and administrators.

Section 4.1.7 introduces a second, distinct treatment delivery alternative to typical urban hospital-delivered chemotherapy: the concept of 'closer to home' chemotherapy. We define this 'closer to home' model as chemotherapy delivery in rural areas at non-specialized local clinics or hospitals and managed by general practitioners, usually in linkage with a hospital oncology unit located elsewhere (in the case of Québec) or a regional cancer centre (in the case of Ontario and British Columbia). As will be seen later in this report (see sections 4.2.2 and 5.1.3 in particular), the 'closer to home' model is important in the rural setting where home chemotherapy is unlikely to be available or possible for cancer patients, if they wish to remain in their region of residence during treatment.

4.1 TRENDS IN CURRENT SERVICE PATTERNS IN QUÉBEC

4.1.1 Description of home chemotherapy services studied in Québec

On the basis of our contacts, home chemotherapy appears to be generally available through urban hospitals in Québec for a minority of eligible patients. The components of different home treatment programs varied with respect to a number of factors, including structure, use of specific program guidelines, emergency procedures, and staff (number and types involved). We are able to present some general trends on availability based on our interviews at eight urban centres, including several teaching hospitals and a pediatric hospital. In section 4.1.7 we present information based on our interviews with two rural care providers.

We found that home chemotherapy programs could be offered through oncology day hospitals, through oncology inpatient units, or through oncology outpatient departments. At three sites both the outpatient and inpatient oncology departments were formally involved in a joint service, but at another hospital these were two separate programs. Some programs had started recently, in the last 1-2 years, but two institutions had offered the service for 10 years or longer. The programs tended to be set up in response to inpatient bed shortages, and initiative on the part of nurses and pharmacists had played a large role in their establishment. In terms of

patient numbers some hospitals were treating 1-2 patients per month at home, while for others this was 4-5 or 6-7 patients/month, or as many as 9-10/month. One site treated 840 patients a year at home, representing about 20% of their chemotherapy patients (and demand was expected to increase). Annual statistics for a *Centre hospitalier de l'Université de Montréal* (CHUM) hospital for April 2000-March 2001 showed that about 4% of chemotherapy treatments were delivered at home (279/7,134), representing 117 cancer patients. At this site, however, the number of patients who would receive home therapy in the next year was expected to double to 250.

We focused our emphasis in the interviews on use of intravenous chemotherapy at home. (Oral chemotherapy, also an important treatment method and not without risks, was found to be offered separately through outpatient departments and did not appear to belong to a specific 'program'.) Home programs for adults generally provided continuous infusion treatment with programmable pumps. None of these programs included on-site supervision during treatment by a nurse. Three sites used balloon infusors: at two, this was in addition to pumps whereas the third site was planning to extend his program and start using pumps. One site was not satisfied with infusors and used pumps instead. The most common treatment was a 4 to 5-day infusion of 5-fluorouracil (5-FU). Other protocols included vincristine-adriamycin-dexamethasone (over 4 days), cisplatin-doxorubicin (over 2 days), and combinations with 5-FU, such as 5-FU-oxaliplatin-leucovorin (over 3 days). At the pediatric hospital the home program was targeted to leukemia in the maintenance phase and consisted of teaching parents to administer intramuscular injections of methotrexate at home without on-site nurse supervision once a week for 2-2.5 years.

As will be discussed further in section 4.1.5, the use of CLSC services in these programs was very variable. Home visits by an oncology nurse during treatment were not provided by any of the programs. The frequency of necessary patient visits to the hospital varied across sites. At one institution the patient needed to return every 72 hours to have tubing checked; at others the patient came in on the first and last day of treatment (thus potentially 2 times/week for a 5-day regimen). When the inpatient department was involved there was more flexibility in that treatment could end on a weekend and the patient could have the equipment removed by an inpatient nurse. At one site treatment was started every 2 weeks in the outpatient unit and the infusor was disconnected at the patient's local CLSC or by a CLSC nurse visiting the patient's home.

4.1.2 Patient eligibility criteria

Central line access was used for intravenous home chemotherapy at all sites; most services also used PICC lines. At most institutions an informal support person for the patient was advised but not mandatory; one site required someone to be at home during infusions (e.g. family member, neighbour). The types of cancer in adults that were treated at home included colorectal, anal, esophageal, head/neck, gynecological, lymphoma, and multiple myeloma. In general, patients had to be medically stable and possess an acceptable level of functional capability. The treatment protocol had to be one suitable for delivery at home. Close proximity to a hospital was a requirement at several places (e.g. within 1 hour drive). At one site, only residents of a specific urban region were eligible for home treatment. Cancer patients could come from all over Québec for diagnosis and treatment at urban teaching hospitals. Only at the pediatric hospital did there seem to be any system in place for patients to receive chemotherapy in or closer to their region of residence, if they were not living in an urban area: pediatric leukemia patients could receive their weekly injections from a local pediatrician. Blood tests were taken at all sites prior to each therapy cycle, in order to determine the patient's suitability for treatment at a certain time. Not every site insisted that the first treatment cycle had to be administered at the hospital.

4.1.3 Role of hospital staff

Nurses at each site had a large role in determining a patient's eligibility for home chemotherapy. Referral to the service by a physician was followed by a detailed assessment by a nurse, who then gave the patient education and training if the home option was accepted by an eligible patient. Although the pharmacy department at each site was always responsible for preparing the medications (e.g. priming and programming the pumps, providing drug dosages in syringes for injection), two teams specifically included a pharmacist who had a role in patient assessment and training, and who could be contacted directly by the patients during office hours for technical problems with the pump or infusor. At most sites we spoke to, patients phoned day hospital or outpatient nurses during weekdays if necessary for clinical problems. Outside of office hours, however, the contact strategy differed widely from site to site: at some institutions the patient had to go to emergency (after phoning an oncologist on call at three places); at other hospitals, inpatient nurses were accessible by telephone 24 hours each day and patients were seen at the inpatient department if necessary, rather than being sent to an emergency room.

Two of the more formalized programs had a full-time staff nurse working in home chemotherapy. One of these spent half of her time teaching patients and the rest of her time managing the home program. Other sites did not have nurses specifically assigned to the service, but one institution had a unique system whereby each oncology patient was assigned a primary nurse who provided training and maintenance, and was responsible for supervising any home treatment. Some hospitals had nurse coordinators, liaison nurses or in-charge nurses involved in home therapy, in addition to the pharmacist and oncology nurse(s). At one site patients had the option of being phoned each day by an oncology nurse. At another site, patients were supported by a multidisciplinary team consisting of a pharmacist, liaison nurse, social worker, dietician, symptom management nurse (through a research project), an oncology psychiatrist and his nurse, a palliative care team, and community support groups.

4.1.4 Cost issues

At all but one of the sites we interviewed there was no specific budget for home chemotherapy: the cost of hospital nursing time was paid from the regular staff budget of the department responsible. One site had a specific program budget with nursing time dedicated to the service; as a result of these additional resources, workload did not increase in this outpatient department with the start of the program. Purchasing pumps was the most costly expense ($4,000-5,000 CAN each). Costs of chemotherapy drugs and equipment were paid by the hospitals (pharmacy and nursing departments). Where CLSCs were more involved the CLSC paid for home nursing time and supplies such as dressings and line flushes.

The alternative to home intravenous therapy at all sites was being admitted for inpatient treatment. Each program was perceived as saving costs to the health care system, despite some increases in equipment costs (e.g. special tubing was 10 times more expensive for the home setting; non-reusable balloon infusors cost $30-48 per treatment). At *Hôpital Maisonneuve-Rosemont*, a hospital affiliated with University of Montreal, statistics for March-December 2000 showed that home treatment saved 897 days of hospital admission for 45 patients, while requiring 453 nursing hours for the delivery of 299 treatment cycles. No data were provided regarding pharmacy costs [Bélanger et al., 2001]. Several interviewees pointed out that their program saved additional costs by preventing emergency room visits and medical complications. It was also asserted that the extent of nursing activity spent on home chemotherapy was underestimated by statistics referring to the number of patients treated or number of treatments delivered. Such counts do not reflect nursing time spent on patient follow-up, documentation and patient information systems, nor handling telephone calls from patients. They likewise do not reflect increased pharmacist time spent on treatment preparation, planning and organization, teaching how to use the equipment, nor responding to patients' concerns. In the case of pediatric leukemia patients, injections by parents at home saved the family three visits a month to the outpatient clinic.

4.1.5 Role of CLSCs

Involvement of CLSC services was highly variable. At several sites CLSC nurses were sometimes used to visit the home patient in response to a problem or to disconnect the equipment. CLSC nurses visited patients from one site after therapy was finished to irrigate the catheter, administer other medications (non-neoplastic), and evaluate needs for home help. In comparison, three sites specifically referred home patients to their local CLSC (if urban-dwelling) for line support and management. At one hospital the communication links with CLSCs was particularly close, with a patient information sheet being automatically sent to the CLSC (as well as the inpatient department) for all patients sent home with infusors by the outpatient team. At another location the four local CLSCs were considered partners in the home program. At one site patients in active pump treatment rarely required a home visit; a request to a local CLSC for home care (often then referred by the CLSC to the Victoria Order of Nurses or Entraide Ville-Marie) was made much more often for palliative patients needing pain control. In general where cancer patients were concerned, CLSC nurses appeared to be more involved in home administration of pain control, subcutaneous chemotherapy injections, antibiotic therapy, and palliative care. As will be discussed further in section 4.1.7, several of our contacts felt there needed to be greater exchange of expertise between hospital oncology and CLSC nurses in order for the latter to provide more supportive care.

4.1.6 Patient satisfaction

As mentioned in section 3.4.3, one of the sites we visited had recently completed a program evaluation based on self-administered questionnaires filled out by 32 home chemotherapy patients (out of 45 served over 10 months; response rate: 71%). The majority of patients in this study appeared to feel positive about the service (results are summarized in Table 5, p. 35). A second site was using questionnaires to study patient quality of life, satisfaction, and accessibility issues within their service but had not yet completed a report.

In general, the nurses we interviewed had witnessed mixed patient reactions to the possibility of having chemotherapy at home. Initially, patients had many questions and concerns and were sometimes very anxious about the idea. A few patients had expressed a feeling of being deserted by nurses to do their own care. Nurses found that, for some patients, having the experience of the first treatment in hospital and/or receiving extensive training resulted in a positive response and opting for home therapy. Nurses at one site mentioned that younger patients adapted more easily to home treatment. One contact stressed that the patient (and at least one of his/her family members) need to be motivated to handle chemotherapy at home. Anecdotal feedback from nurses at several hospitals showed that participating patients tolerated the process well, liked the chance to be at home, preferred not to be hospitalized, and learned more about their treatments. Home therapy was clearly favoured over waiting for in-hospital treatment. Several contacts felt it was important to stress that the patients making these decisions are seriously ill and above all wish to have effective treatment as soon as possible.

4.1.7 Rural Québec settings

At both rural sites included in our interviews home chemotherapy had started recently, in the last 6 months, and they had thus delivered home treatment to a small number of cancer patients. One site was located close to a city but served a large, distant rural area. The other hospital was remote; the nearest oncology unit in a regional hospital centre was a 3-hour journey away (in good weather), involving driving and a ferry. At one location balloon infusors and PICC lines were used for 4-5 day continuous therapy following a first treatment cycle in hospital; this regimen was implemented for esophageal cancer only. Patients were trained in the outpatient department by a nurse and pharmacist; for problems, they could call outpatient nurses during office hours and the CLSC or emergency room otherwise. Patients were referred to their local CLSC for dressing changes and line flushing, which was either done at the CLSC clinic or at home. It was possible for patients to return to a rural area of residence while being treated

(depending on the therapy schedule), but they often chose to stay in the less rural setting near the hospital in motels or with family/friends. Patient response to home therapy had been positive (although some patients were too nervous to participate), training was perceived by nurses as fairly simple, problems had not been encountered, and the program was considered easy to manage.

The second rural site was a good example of 'closer to home' chemotherapy. An oncology clinic established at the local hospital delivered all chemotherapy (except experimental regimens), with the support (at a distance) of three hemato-oncologists at the larger regional hospital. The oncology clinic included 7 general practitioners, 3-4 nurses, a pharmacist, psychologist, social worker, and dietician. Surgical diagnostic services were also available locally. All chemotherapy protocols and prescriptions were approved by the consulting oncologists who visited once a month for a 3-day period. Both infusors and pumps were used and 250 cancer patients residing up to 150 km away were currently being followed. Patients coming to the clinic for therapy from far away had their blood tested in their community before travelling. Twenty-five percent of the hospital's budget was spent on the oncology clinic. Home treatment started in 2001 in response to a particular patient's demand for the service. Home visits by CLSC nurses had been difficult to arrange primarily due to the nurses' anxiety about managing cancer patients.

Our contact noted the importance of gaining the patient's confidence in the level of care offered by the rural oncology clinic. Patients also needed the constancy of the same treating physician. Staff (both nurses and doctors) required training, support, and experience in order to feel comfortable with their oncology responsibilities. The general practitioners (who were able to choose whether they participated in the oncology clinic or not) were given 6 months of physician back-up at the start of their involvement. The time-consuming and potentially distressing nature of cancer care meant that family physicians working at the clinic required enthusiasm, empathy, compassion, and maturity.

4.1.8 Organizational barriers and challenges

A number of organizational barriers and challenges to providing high-quality home chemotherapy programs in Québec were raised during our interviews. These are summarized in categories below.

- Limited resources

This was the factor that was endorsed the most frequently in our interviews. Contacts referred to a lack of specific budgets for home treatment (except at one site), a lack of oncology nurses and pharmacists, a lack of equipment (e.g. programmable pumps costing $5,000 each), and a lack of financial resources for home visits and in-department training. None of the programs we studied allowed for home visits by oncology nurses.

At one site it was felt that physicians would refer more patients to the service if the department owned more pumps, but that this, in turn, would require more nursing resources and safety procedures to handle the increased patient volume. It was generally felt that demand for home chemotherapy will increase, but current budgets would restrict how much service delivery could respond to this demand. The transfer of patients to the home was thought to require more resources in outpatient departments.

- Requirement for a high level of nurse/pharmacist commitment, training, and autonomy

Contacts highlighted the close link between appropriate delivery of home chemotherapy to patients and sufficient oncology expertise and commitment to patients on the part of nurses. The importance of careful patient selection, education, management, and follow-up was stressed at many sites. Such tasks require highly knowledgeable, specialized nurses and pharmacists with decision-making autonomy. Interviewees at several sites felt that there was underrecognition of the extent of nursing activity involved, of the nurses' extensive contribution to patient education in these programs, or of oncology nursing as a speciality in general.

- Lack of collaboration between centres / no designated cancer centres

Based on our interviews, an ad hoc set-up of home chemotherapy programs through individual hospitals with oncology units has occurred at a number of sites, without a concerted effort at the regional level. At one site, our contact spoke about the difficulties of organizing and standardizing home treatment with so many different hospitals and CLSCs in the urban region; it was perceived as easier to establish a program with efficient continuity of patient care in areas with fewer service providers. It was our impression that it is difficult for hospitals to learn from each other given the general lack of awareness of available home treatment programs. Another contact commented on the lack of designated cancer centres in the province, where oncology services and expertise is concentrated. This cancer centre concept will be explored in more depth in section 4.2 on the basis of information from Ontario.

- Need for nursing and medical support

A few contacts highlighted the importance of both nursing and medical support in a home chemotherapy program. This factor relates to the nursing skills previously described but also the availability of suitably trained home visiting nurses and an efficient process of referral to such services (see next category). Medical back-up was also stressed as an integral part of home treatment, as well as for 'closer to home' services managed by general practitioners. One contact suggested the need for a 'quick track' method to admit home chemotherapy patients to the hospital if necessary for complications.

- Lack of organized collaboration with CLSCs

Most sites felt there needed to be greater involvement of CLSC nurses in their program, but that in order to do so it was necessary to have more teaching materials for the CLSC and greater sharing of expertise between oncology and community nurses. One contact believed home chemotherapy provided potential for useful exchange between hospitals responsible for specialized oncology treatment and CLSCs responsible for simpler nursing support (e.g. maintenance of lines, connection and disconnection of equipment). It was pointed out that CLSCs also needed more resources in order to provide home support. In the absence of home visits by oncology nurses, there is a possibility for an increased role for CLSC nurses in the support of home chemotherapy.

An unequal level of CLSC support across regions was noted at one site. At another, our contact felt it was inappropriate for cancer patients to have to visit CLSCs in order to receive care, rather than receiving a home visit. One rural contact in particular spoke about wanting to break the barriers to greater CLSC involvement, such barriers being related in a large part to the CLSC nurses being scared of managing cancer patients.

- Need for program standardization and formalization of multidisciplinary teams

There was a general consensus that home chemotherapy service teams needed to be multidisciplinary, composed of physicians, oncology nurses, pharmacists, and home nurses. A few sites went further to suggest a need for standardization of home chemotherapy care through common clinical and safety guidelines and decision-making protocols. Hospitals in the same city used different equipment and procedures. The establishment of across-province guidelines was highlighted as the biggest organizational challenge at one site. Related to this issue was a perceived need for standardized models of home chemotherapy programs, as well as program evaluation.

4.1.9 Facilitating factors

The most commonly reported factor that facilitated the establishment of the home chemotherapy programs was hospital personnel initiative. Teams at several sites had looked at what other countries were doing in home cancer care; one nurse-clinician and pharmacist team had studied the scientific literature while setting up their program. In terms of maintaining high quality service, one interviewee pointed to the extra nursing time devoted to extensive patient follow-up, regular patient contact, and thorough documentation; this was echoed by another team whose use of a coordinated, standardized information sheet kept three locations aware of the

patient's chemotherapy treatments and contributed to continual follow-up. This same team highlighted the importance of their communication links with the CLSCs. At one site the benefits of a primary nurse system for patient follow-up was emphasized. Constancy of human contact, then, was a clear recurring theme.

The one location with a specific home chemotherapy budget pointed to these dedicated financial resources as a facilitating factor. This contact also mentioned that using drugs with lower toxicity at home helped reassure both patients and nurses. Finally, the 'closer to home' program we heard about showed that specialized training of nurses and general practitioners, as well as good communication links with oncology consultants and a period of back-up, were essential for chemotherapy delivery in a rural hospital clinic.

4.2 COMPARISON WITH TRENDS IN SERVICE PATTERNS IN ONTARIO

4.2.1 Organization of oncology services in Ontario

The cancer treatment and control services in Ontario have been coordinated by an administrative body (Cancer Care Ontario) since 1997 and are based on a comprehensive, integrated model (CCO, September 20, 2001). Cancer Care Ontario (CCO) is the principal advisor to the provincial Ministry of Health and Long-Term Care. CCO's mandate encompasses the full spectrum of cancer control activities and cancer care system planning, and includes the development of clinical guidelines and care standards. Its network includes the Program in Evidence-Based Care, the Ontario Cancer Prevention Network, the Ontario Breast Screening Program, the Ontario Cervical Screening Program, the Ontario Cancer Registry, the Ontario Cancer Genetics Network, the New Drug Funding Program, and operation of the province's nine regional cancer centres (which are directly accountable for implementing provincial policies and guidelines).

At the regional level, eight Cancer Care Ontario Regional (CCOR) councils—composed of patients, physicians, and representatives of hospitals, district health councils, Community Care Access Centres (see below), and the Canadian Cancer Society—currently advise on the needs of their areas, participate in system planning, and oversee regional integration. A restructuring process is now underway and CCO recently submitted a report on a "Model for the Governance and Management of Cancer Services in Ontario" to a Cancer Services Implementation Committee struck by the Ministry in June 2001 (CCO, November 15, 2001). The two CCO reports submitted to this Committee in 2001 were used to describe the organization of services below.

The nine regional cancer centres (RCCs) in Ontario deliver 75% of the province's radiation services and over 50% of its chemotherapy, in an outpatient setting. The overall operating budget of these centres (administered by CCO) is $154 million; in 2000-2001, 113,000 patients were treated (more than 50,000 people are diagnosed with cancer in Ontario annually, and there are currently about 225,000 prevalent cases). About 50% of cancer patients in Ontario are treated with chemotherapy. Outside of the Greater Toronto Area, almost all chemotherapy is delivered under the direction of the RCCs.

Each RCC is coupled with a host hospital that delivers inpatient oncology services and surgery, as well as diagnostic services. Most of the RCCs also have affiliations with community hospitals in more rural areas that provide prediagnosis work-up and surgery (especially for common cancers); in many regions, patients return to their local community hospitals for chemotherapy after evaluation and treatment prescription at RCCs (more details on rural services will be presented in section 4.2.2). Most of these linkages involve shared funding of chemotherapy costs and close liaison between staff so that more rural patients have the same access to care as those in the catchment areas of the host hospitals, and can receive treatment 'closer to home'. CCO

has successfully managed the formation of relationships between community hospitals and RCCs in part because the latter are not viewed as competitors by the former.

In 1996 the Ontario Ministry of Health created a system of Community Care Access Centres (CCACs), to coordinate home care services throughout the province (as well as admissions to long-term care facilities). There are currently 43 of these centres across Ontario. Visiting nurse services (for support of chemotherapy, for example) can be purchased from professional organizations by CCAC case managers on behalf of eligible consumers; this is entirely funded by the Ministry of Health and Long-Term Care.

4.2.2 Description of home chemotherapy services studied in Ontario

The structure of cancer and home care services in Ontario appeared to contribute, in general, to greater availability of home chemotherapy services at the sites we contacted, in terms of capacity for greater patient load. Our Ontario interviews included an urban cancer hospital for adults, three regional cancer centres (one situated in a remote area), an urban pediatric hospital, and Cancer Care Ontario. One regional cancer centre had been offering home chemotherapy for more than 15 years (and currently served about 50 patients/month in the Greater Toronto Area), while other sites had begun the service in the past 2-3 years. At two of the three urban adult institutions included in our interviews, all multi-day continuous infusions were delivered at home using pumps (without continuous on-site supervision by a nurse); if home treatment was not possible the alternative was a different type of regimen, delivered on-site in the outpatient department.

At the urban cancer hospital studied, the home chemotherapy team consisted of three Community Care Access Centre (CCAC) 'care coordinators' on site, an intravenous company which provided the chemotherapy drugs, equipment, delivery/pick-up services, and blood testing, and a nursing agency which provided home visits for treatment delivery of subcutaneous injections and line changing for infusions by pump (every 48 hours). The nursing agency was responsible for its own training and certification, and patients had 24-hour/day telephone access to the intravenous company and nurse triage. It was also possible for patients to reside at a CCAC urban lodge and receive outpatient therapy at the hospital.

Interviews at the two urban regional cancer centres were conducted with one nurse coordinator/manager at each site, as well as with an oncologist at one of these centres. The centre with the older home infusion program owned more than 40 pumps and the team was composed of a manager/supervisor, the RCC pharmacy, and three nurses; no home visits were provided. The venous access device was put in place at the RCC and continuous infusions could be prescribed for 4 days to 5 weeks in duration. At the hematology site of this RCC, our oncologist contact described the home infusion program for adults with acute leukemia living within 1 hour of the centre. These patients required expert nursing care and were seen weekly at the RCC as they had many treatment needs (e.g. transfusions). About 50% of such patients received infusions at home with pumps (without continuous on-site supervision), representing 7-8 patients per year. The alternative to home treatment was therapy as inpatients in the host hospital.

At the second urban RCC, the home continuous infusion pump program had operated for the past 2 years, delivering multi-day treatment to 1-2 patients living in the urban catchment area (within 30-45 minutes) per month. A multidisciplinary team was involved, consisting of a nurse clinical coordinator and CCAC case manager (both of these on site), visiting nurses from an agency (trained/certified by the RCC), and a retail pharmacy. Patients were visited at home daily, received training from the visiting nurses, and had 24-hour/day telephone access to on-call nursing staff. The first treatment was delivered at the cancer centre and patients visited the RCC again before each therapy cycle. In terms of alternatives to home treatment, patients in the urban catchment area were admitted to the host hospital; patients from further away could receive

chemotherapy during the week as outpatients at the RCC or at an affiliated residential lodge (going home on weekends). The centre was also involved in training family doctors at community chemotherapy clinics in rural hospitals; this program will be discussed in more detail below.

In the pediatric setting, our contact at an urban children's hospital informed us of a randomized crossover study which began in 1999, and which was in the mid-stage of data collection. This was the only Canadian randomized study we identified in our literature search and interviews, and we present some details here about the program and research design. Patients 2-16 years old with acute lymphoblastic leukemia and receiving treatment for the first time (i.e., not in relapse) are being enrolled from the Greater Toronto Area. Study participants receive 6 months of treatment at each of two sites: hospital and home (with the order being randomly determined). Depending on the phase of the young person's illness, chemotherapy is delivered by a nurse from 3-4 times/week to once every 2-4 weeks. At the hospital site, blood tests are completed and therapy is then received in the outpatient department. At home, blood is tested at a community laboratory, results are faxed to the primary care nurse oncologist at the hospital, intravenous drugs are prepared and delivered by a community pharmacy, and a home care visiting nurse delivers the entire treatment. Parents provide supportive care. During the home phase, about half of the total care can be delivered at home.

Data are being collected from parents (and patients if older than 6 years) every 3 months and include patients' and parents' quality of life, family burden, costs (both direct and indirect), occurrence of adverse events, and requirements of care providers (regarding knowledge and resources). Based on the first 11 cases, results show a decreased number of missed school days, decreased nausea and vomiting, and increased psychological comfort for the patients when treated at home. Parents indicate reduced costs (e.g. for travel and babysitting), decreased burden, greater flexibility in treatment schedule, and satisfaction with the quality of home care received.

In the remainder of this part we discuss chemotherapy services for rural adult patients in Ontario, on the basis of interviews with Cancer Care Ontario and a rural regional cancer centre serving an extremely large northern area. A network of 44 community or 'satellite' clinics in small town hospitals delivers chemotherapy 'closer to home' across the province. The development of this network has been partially in response to increased patient advocacy and pressure from patients for more accessible diagnostic services and chemotherapy. As mentioned in the previous section, these clinics are linked to the nearest RCC for professional training and certification (of family doctors, nurses, and pharmacists) according to CCO standards. The clinics are ranked according to their level of experience, and this ranking determines which treatments can be offered.

Our contact at the rural RCC works with 13 satellite centres in an area the size of France. The RCC trains family doctors from communities for 2-3 days a year, provides an annual review of potential emergencies, and maintains frequent contact with the rural physicians (with monthly teleconference rounds, for example). In the communities, most sites deliver chemotherapy in the emergency room; three hospitals have separate treatment rooms. Nurses are relieved from their usual hospital duties to administer treatment when needed, following standard policies. At some sites nurses also prepare the drugs if there are no pharmacists. The entire chemotherapy regimen can be delivered locally after receiving diagnosis and treatment prescription at the RCC. The biggest advantage to the patient is clearly decreased travel time and costs. Some patients can have infusion therapies at home using a pump, hooked up at the community hospital. These patients have 24-hour/day access to a physician and go to the local emergency if necessary.

4.2.3 Organizational issues raised by Ontario service providers

A number of organizational issues were highlighted in our interviews with chemotherapy providers in Ontario. These are summarized in three categories below.

4.2.3.1 Cost issues

In terms of paying costs, responsibility was generally shared between the various organizations involved in home chemotherapy with little or no treatment costs to the patient. At the urban cancer hospital, for example, CCAC paid for catheters and drug delivery out of its budget (from government transfer payments), rented pumps from the intravenous company, and billed the health ministry for the cost of home visits by agency nurses. At one urban regional cancer centre the home chemotherapy budget was restricted to 1.2 nursing days/week (considered a separate service; no home visits); in addition, the RCC paid for catheters, lines, and pumps while the host hospital paid for access devices and the ministry covered drug costs.

In comparison, at a second RCC the home infusion program did not have a specific budget and nursing time was considered part of the general work. At this site, the visiting nurse agency (daily home visits) billed CCAC (who in turn billed the government) and the retail pharmacy drugs and equipment were paid for directly by the health ministry. This was the only program we studied which involved a charge to patients: a $2 charge for delivery from the community pharmacy. The services provided through the randomized study at the pediatric hospital represented zero actual costs since the research was funded by a foundation and Health Canada. Finally, in the rural 'closer to home' chemotherapy network drug costs were paid by the RCC involved while each community hospital paid for its own staff time and supplies.

Regarding savings offered by home chemotherapy programs, one site provided the following comparison: home treatment cost $200 daily (nursing and supplies) while hospital admission was $1,500 per day. (The base rate for a hospital bed at the Montréal General Hospital is $681 per day, not including any oncology interventions [source: Admitting Services, 2002]; the average cost of an overnight hospital stay for a breast cancer patient in Québec is $1,115 (for the lowest condition severity level; [source: Med-Echo 1998-99]). As discussed previously, however, the hospital savings can be limited or non-existent when outpatient treatment is a feasible alternative to home therapy. On the basis of 11 study cases, the pediatric hospital contact reported no overall difference in costs when considering the perspectives of both the institution and the patient: while costs to the family decreased, care delivery costs were higher at the home site.

One of our Ontario contacts suggested that a desire to save costs should not be the motivation for establishing home chemotherapy programs, as such programs are not likely to result in closure of hospital beds. Rather, beds freed by relatively ambulatory patients sent home to receive chemotherapy may tend to become occupied by sicker oncology patients requiring more intensive, costly treatment. This point was, in fact, also raised by one of our urban Québec contacts, and has been argued by Thickson in his review of economic issues in home intravenous therapy [Thickson, 1993].

4.2.3.2 Facilitating factors

The following factors were felt to be important facilitators, contributing to the establishment and/or success of the home chemotherapy programs we studied in Ontario.

- Owning pumps

At the RCC site with the oldest program, equipment ownership was considered essential. Maintaining pump expertise was also endorsed.

- Interest of physicians in home treatment

This factor was mentioned with reference to both the regional cancer centre and rural community hospital settings. At the rural RCC innovative oncologists were credited with initiating satellite clinics in their region.

- Openness to innovation

At one location the nursing team had an active role in developing new treatment regimens that moved patients out of hospital beds and into the home. The same team had also developed a patient information booklet.

- Targeting a few disease sites; small number of staff serving large number of patients

These factors were viewed as important for keeping programs simple and fostering good team communication.

- Collaboration with community services

If we include the pediatric setting, three of the four urban programs studied involved the collaboration of CCAC staff to coordinate the home nursing (the actual care being delivered through nursing agencies like Victoria Order of Nurses). The pediatric randomized study represented a three-way collaboration between the children's hospital, a university, and the community, the last of these represented by CCAC and a visiting nurse organization.

- Training of community organizations/ suppliers

This was an important factor for programs that relied on services originating from the community.

- Sufficient outpatient resources

These were viewed as important for ensuring service coordination and safety, even though treatment was being delivered at home.

- Careful patient selection

This was highlighted by our contact at the pediatric hospital involved in the research study. It was considered important to be able to anticipate which families would be able to manage home care. Some study parents indicated feeling somewhat burdened by case management, in that they had to interact with multiple parties: the community laboratory, the community pharmacy, visiting nurses, and hospital nurses.

Some additional factors related specifically to 'closer to home' chemotherapy at rural community hospitals, and are listed below. (This delivery setting will be explored further in section 5.1.3.)

- Endorsement at provincial and regional levels
- Community receptivity and involvement

This included program endorsement by leadership at the community hospitals and by the family doctors. At some rural sites the community had been greatly involved in raising money to decorate and furnish the clinics in order to create a patient-friendly and relaxing atmosphere.

- Certification of rural cancer clinics

Ensuring the same quality of care in the community—and visually displaying certification—was deemed essential for treatment effectiveness and to attain patient confidence.

- Initiative of community nurses

The rural RCC contact credited the local community nurses for their initiative in completing the specialized oncology training. Problems with not having enough nursing staff in the rural regions posed difficulties for professional education; it was difficult for local nurses to find time to travel to the RCC for a week of college-accredited training in chemotherapy and central line management. At the time of interview, the nurse manager at the RCC (now partnered with a nursing educator) was planning a visit to each satellite community once a year, as well as other alternatives for localized training (e.g. teleconferencing). The success of the nursing training was encouraging the RCC to seek additional educational funding as well as to establish 20-30 hours of instruction per year in order to keep the nurses certified (100 training hours or an examination every 5 years is required for oncology certification). Drug information sheets have been set up on-line, and an oncology patient information system is planned. A conference for nurses is held each year at the regional cancer centre.

- Ongoing support and maintenance

According to one contact, the regional cancer centres have been seen as neutral brokers in the establishment of satellite clinics; the regional sites provide a concentration of oncology expertise and are not hospitals themselves. At the rural RCC the head of systemic therapy was in frequent contact with the community physicians (often weekly), in addition to the monthly rounds by teleconference (which could include local nurses and pharmacists) and an annual conference. The 13 northern communities received visits by an oncologist 3 times per year; an oncology nurse was also available if more than

50 patients were expected over a few days. These visits included an educational component with the local team.

4.2.3.3 Barriers

The service barriers most frequently mentioned by the Ontario contacts were restrictions in human and financial resources. At one site treatment delays could occur due to insufficient human resources; also, treatment cycles were sometimes lengthened if there was no bed immediately available for the next therapy stage. Lack of nursing resources was highlighted as a barrier at several locations. Budget cuts at CCAC were held responsible for limiting home care services. Funding was needed at the rural RCC for training of community nurses. There also appeared to be a general difficulty in finding time or resources for formal evaluation of the programs we considered.

4.2.4 Conclusions

Through a comparison of the information we collected from service providers in Québec and Ontario it appears that the structure and financing of cancer and home care services in Ontario contributes to a capacity for greater patient load, greater uniformity of services, and inter-organizational collaboration that is more fully supported and developed. Access to chemotherapy both at home and 'closer to home' is facilitated in Ontario by centralized funding, a regionalized approach, support of alternative outpatient delivery (fostering liaisons between cancer centres and community hospitals), involvement of general practitioners in a network of rural chemotherapy clinics, access to oncology expertise through communication links, and certification of community chemotherapy clinics. Unlike at the Québec sites we interviewed, home nursing visits during treatment (but not continuous on-site supervision) were an integral part of the home chemotherapy program at three of the four urban Ontario hospitals we studied. Organizational issues highlighted by contacts from both provinces related to the need for collaboration with community-based services, the importance of initiative and support of a multidisciplinary team, the role of nurses and pharmacists in program management, patient education, and home support, the need for sufficient outpatient resources, and the importance of communication and training links between different team members involved in home and 'closer to home' treatment.

5 ORGANIZATIONAL, ETHICAL, AND LEGAL ISSUES

5.1 ORGANIZATION OF SERVICES

The delivery of cancer chemotherapy at home clearly requires high quality, integrated services by a specially trained, multidisciplinary team in partnership with motivated, trained patients and their caregivers. This is particularly important for intravenous home chemotherapy but is also relevant to some extent for oral treatment and other delivery methods at home. In section 5.1 we return to the scientific literature to augment our discussion of the organizational issues raised by our interviews with service providers in section 4. In the first part of section 5.1 we briefly examine a number of intra-organizational issues which must be managed at the individual sites involved in a home chemotherapy program (e.g. hospital oncology department, pharmacy, visiting nurse organization or CLSC). We then look at inter-organizational issues, focussing on the relationship between the different service providers in a comprehensive home chemotherapy team. We discuss the issue of outpatient alternatives to home care ('closer to home' chemotherapy) in more depth. Keeping in mind the current existence of home chemotherapy programs in Québec, we conclude the section with a summary of the conditions that need to be satisfied for high quality services. Section 5.2 is devoted to an examination of the ethical and legal issues surrounding cancer chemotherapy at home.

5.1.1 Intra-organizational issues in delivery of home chemotherapy

5.1.1.1 SPECIALIZED NURSING TRAINING AND RESPONSIBILITIES

Oncology nurses involved in home chemotherapy require specialized skills in chemotherapy administration and patient teaching [Garvey, 1987]. Since these nurses work in the hospital setting, they are often the first source of information for patients considering home treatment. Their expertise in handling pumps, venous access devices, lines, intravenous tube insertion, chemotherapy drugs, and other medicines (such as anti-emetics)—in conjunction with the oncology pharmacist—is crucial both for treatment delivery within the institution and for the transfer of these skills to visiting community nurses and to the patients themselves. The oncology nurse's role is expanded in a home chemotherapy program to encompass patient assessment for home care and selection of eligible patients [Gorski and Grothman, 1996]. A number of factors are important for a comprehensive patient assessment, including his/her diagnosis, prescribed treatment(s), medical history, other health problems, physical care needs, requirements for laboratory work, psychosocial needs, self-care capability, ability to follow directions and learn technical skills, level of support, and home environment [Lowdermilk, 1995; Ophof et al., 1989; Garvey, 1987]. Careful selection of eligible patients requires decision-making autonomy.

Nurses who go into the home to administer chemotherapy or assist with its delivery require sufficient training in handling the drugs and equipment outside of the hospital environment and in managing side effects and adverse reactions [Garvey, 1987]. According to Parker, mixing and preparation of chemotherapy drugs should be the responsibility of the oncology pharmacist (either at the hospital or in the community, where possible) so that the nurse does not have to do this in the home [Parker, 1992]. The visiting nurse must be alert to the signs of anaphylaxis and extravasation and be adequately prepared to respond [Garvey, 1987]. This nurse will need to be independent, a good communicator, and comfortable with a flexible working schedule [Gorski and Grothman, 1996]. Chemotherapy and cancer care education for all nurses involved in home treatment should be ongoing in order to maintain high skill levels [Parker, 1992] and certification by professional organizations.

5.1.1.2 ADHERENCE TO CARE AND SAFETY POLICIES

Home chemotherapy procedures must follow treatment and safety protocols that represent best practices. The establishment of these policies is critical for the set-up of a home care program. Their completeness and standardization is facilitated through the contribution of physicians, nurses, and pharmacists in policy development and consistency with procedures imposed by regulatory bodies. Specific procedural topics which need to be addressed include (1) patient selection criteria; (2) drugs eligible for delivery at home by the nurse, patient or informal caregiver; (3) managing peripheral and central venous access; (4) administration of intravenous infusions; (5) managing extravasation and hypersensitivity reactions; (6) safe handling of chemotherapeutic agents; and (7) emergency responses and patient contact system [Gorski and Grothman, 1996]. As mentioned in section 3.3, the *Regroupement des pharmaciens en oncologie* has developed an extensive guide on chemotherapy for Québec pharmacists that includes procedures for home administration.

5.1.1.3 EDUCATION AND TRANSFER OF SKILLS TO PATIENTS AND CAREGIVERS

Home patients require information about their treatment regimen, schedule, and chemotherapy drugs, how therapy may affect their lifestyle, signs and symptoms which should be reported to a medical professional, management of side effects, what self-care they will have to perform (e.g. dressing changes, catheter care, bathing with an attached pump), how to handle their equipment and dispose of drugs and used supplies safely, and what procedures to follow if there is an emergency [Parker, 1992; Garvey, 1987]. Informal caregivers (usually family members) may also need training if the patient needs assistance with care. Patients and/or caregivers need to be both willing to participate in home care and physically and psychologically able to perform the necessary tasks [Dougherty et al., 1998].

Patients and caregivers need the nurse and pharmacist who teach them new technical skills to be patient and compassionate; their learning will also be facilitated by a calm, unhurried approach that reassures them of the professional's competence and support [Lowdermilk, 1995]. Butler described a successful patient education process that included both written handouts and verbal information by the oncology nurse and pharmacist [Butler, 1984]. All aspects of the home chemotherapy infusion service were further discussed and teaching was reviewed with the patient and family members when they returned to the outpatient department for follow-up.

A review of the evidence on cancer patient education methods (based on literature from 1980 to 1991) found that effective learning was promoted through frequent, short training sessions, a focus on information specific to the learner's needs, a structured approach using both oral and written methods, visual demonstration of psychomotor tasks, and reinforcement of learning through follow-up contact [O'Hare et al., 1993]. A study in Ontario found that outpatients who received standardized one-on-one nurse-patient teaching on chemotherapy prior to their first treatment demonstrated a high level of information recall 3-4 weeks later regardless of whether a take-home video was also received (membership in the video group was randomly assigned) [Bakker et al., 1999]. For both the 'no video' (n=30) and 'supplemental video' (n=31) groups, talking with the regional cancer centre doctor or chemotherapy nurse were perceived as the best sources of information, followed by educational pamphlets, and then talking with the primary nurse or family doctor.

5.1.1.4 COORDINATION OF SERVICES

It is somewhat difficult to separate intra-organizational coordination from that between service provider sites due to the multidisciplinary nature of home chemotherapy programs. However, at each site involved, a key person is necessary to coordinate activities in order to ensure comprehensive management of the cancer patient at home. In the oncology department from which home chemotherapy patients are generated, the nursing coordinator of a home chemotherapy program must have excellent organizational and

management skills, in order to oversee the program, plan home treatment, ensure the proper patient training and discharge practices are implemented, maintain contact with and follow the patient over the course of the prescribed therapy, and ensure continuity of care (e.g. by referring the patient to community nursing services for home visits, or to respond to a patient's needs for psychological support or domestic help) [Lowdermilk, 1995; Conkling, 1989; Esparza et al., 1989]. At a home care agency or community nurse organization (e.g. CLSC), a key person is needed to coordinate specialized training of visiting nurses, scheduling of home visits to chemotherapy patients, communication with other personnel (e.g. pharmacists, oncology nurses, physicians, laboratories, domestic workers), and emergency response procedures [Gorski and Grothman, 1996; Garvey, 1987].

5.1.2 Inter-organizational implications: sharing of information, responsibilities, and expertise

A key aspect of home chemotherapy services is the requirement for a team of health professionals from various disciplines to work together. If communication networks are not strong, there is a real likelihood of fragmentation of care. Without efficient and effective collaboration within the team, the quality standards achieved for chemotherapy in the hospital setting will not be present in a home treatment service.

As we saw in the Québec interviews summarized in section 4, collaboration (and clearly communication) between the different health care professionals implicated in home chemotherapy was more difficult when larger numbers of service providers were involved, i.e. many different hospitals and CLSCs. In 1995, the Québec *Comité consultatif sur le cancer* found poor communication to be a particular problem when a patient needed to receive services outside his/her region of residence [Fraser, 1995]. Some physicians in local communities (outside of Montréal) needed to call the oncologists in order to get information about certain interventions delivered to their patients. Exchange of information between members of the patient's health care team was considered essential for the transfer of complete and coherent information to the patient and his/her therapeutic support. The fostering of communication links was an important facilitator of the home chemotherapy programs we included in our interviews (e.g. outpatient oncology—inpatient oncology—CLSC; hospital outpatient nursing—CLSC; consulting oncologists—rural general practitioners; regional cancer centre specialists—community health professionals; CCAC home care agency—visiting nurse organization—intravenous pharmaceutical company). A few of the published studies we reviewed described programs in which a specific multidisciplinary 'coordination team' managed the program, acting as a liaison between the hospital oncology department, home care services, and the patient [Schlag et al., 1989; Lange et al., 1988].

A need for formalization of team functions and responsibilities emerged as another theme in our interviews. Québec health care managers encountered by the *Comité consultatif sur le cancer* disapproved of the absence of formal agreements between health care bodies regarding follow-up of cancer patients [Fraser, 1995]. Links between health care providers were generally formed on the basis of personal connections made during training and practice, rather than through a comprehensive, formalized (yet flexible) network that provides uniform access to services.

Dworkind and colleagues carried out a qualitative study to examine the role of family physicians in cancer care and the relationship between family doctors and oncologists in Canada [Dworkind et al., 1999]. Telephone interviews were conducted with a convenience sample of 116 family physicians from six Canadian provinces (Québec, Ontario, British Columbia, Alberta, Manitoba, and Prince Edward Island). Family doctors wanted to be more involved in the care of their patients with cancer, in order to achieve greater continuity of care. They recognized that cancer care was complex, time-consuming, and more challenging both emotionally and medically than managing patients with other chronic illnesses. They viewed their role as changeable according to the preferences of the

patient and the progression of the disease and treatments. Rural physicians in particular wanted to be more involved in providing chemotherapy and managing treatment side effects. Forty-six percent of urban and 69% of rural family doctors were either willing to deliver chemotherapy in the active treatment phase or already did so (based on an oncologist's guidelines); the principal motivation for this involvement was increased patient convenience. Rural respondents had greater responsibility for inpatient and emergency management of their cancer patients.

From the perspective of the family physicians, the quality of the relationship with the oncologist depended on face-to-face or telephone contact, open and frank communication, clear delineation of professional roles, and whether the oncologist endorsed the contribution of the family doctor to the cancer patient's care. Family physicians needed clear information from the oncologist on prognosis, treatment options, and side effects. Respondents expressed low satisfaction with the existing quality of communication with oncologists; this was an even greater problem when the patient had been referred to the oncologist by another specialist. The failure to negotiate their respective care roles was identified as the major communication difficulty. In two provinces (BC and PEI), the provincial cancer agency was recognized as a promoter of the involvement of family physicians in cancer care; in comparison, the hospital-based cancer care system in Québec appeared to reduce this involvement and weaken communication between specialized and general physicians.

A collaborative approach between specialized oncology and community nursing fields was the model for a pediatric cancer service in Alberta [Burke, 1999]. This could serve as an organizational model if similar initiatives were to be undertaken in Québec. Burke describes a service whereby parental education on central venous catheter care was facilitated by a home visit within 1-2 days of discharge from the pediatric hospital in Calgary. The home session involved an oncology nurse from the pediatric hospital setting (who was responsible for caring for the patient and teaching the family) and a community nurse from a pediatric home care team. The program was planned by both the hospital and home care departments and received the support of senior administrators in the two settings. Twelve home care coordinator nurses were trained at the hospital in a 4-hour session which included three of the hospital nurses. A hospital resource nurse coordinated the joint visits and liaised between the two bodies; she ensured that the home care team received adequate information prior to the visit. Relief staff was used when necessary to cover for the absence of the hospital nurse during the home visit.

Over a 7-month period beginning in July 1996, 12 patients and families received joint visits which involved 8 oncology and 6 community nurses. An evaluation found overwhelming support for the program. The joint visit built on the trust already established with the hospital nurse, helping extend confidence to the community team. Parents became more confident about central line care and were more comfortable and relaxed while being trained in the home. Nurses felt the visits were a valuable addition to the patient's care, allowing evaluation of the prior parental teaching and providing greater support during a period of increased responsibility. Home care coordinators appreciated being able to inform the family of their presence in the community. Nurses from both settings found that the families also needed support regarding issues other than central line management during the visit. The improved quality of care led to incorporation of the program into the standard plan for patients discharged with central lines from the pediatric hospital.

Both of the studies examined above point to the importance of the coordination of chemotherapy services as treatment moves from the hospital to the community and home setting. This coordination, in turn, is related to the overall organizational model for provincial cancer care. Québec is one of only three Canadian provinces that do not have formally structured agencies for cancer control [Carlow, 2000]. A variety of Canadian cancer agency models exist with respect to their responsibilities and level of integration of services, among other factors. Carlow describes how British Columbia has moved significantly towards a comprehensive and integrated system,

with a network of geographically distributed services operated by the British Columbia Cancer Agency [Carlow, 2000].

BC has four regional cancer centres and a Communities Oncology Network, which involves 17 community-based cancer centres (in partnerships with hospitals) and chemotherapy delivery in 22 other community hospitals[13] [Carlow, 2000]. Partnerships relate to funding, professional training, setting of standards, communication links, and coordination of services. The Cancer Agency co-funds the 17 community clinics with the local hospitals; the Agency pays for oncology, nursing, counselling, and pharmacy staff and for medications. A network of 70 pharmacies across BC dispenses chemotherapy 'closer to home'. By funding all oncology drugs the Agency ensures the same medications are available in every hospital. Physicians, nurses, and other care providers jointly develop treatment guidelines for the entire province. These protocols are followed at all chemotherapy clinics. A centralized information system using a high-speed fibre optic network enables the use of one medical record per patient wherever care is received. Five regional cancer advisory committees link to the major cancer centres and the community-based cancer care teams.

Mortality statistics for BC (1994-1996) showed survival rates that were 15% better for males with cancer and 5.6% better for females with cancer when compared to the rest of Canada combined [Carlow, 2000]. While other reasons could explain these favourable outcomes the organization of cancer care delivery in the province may certainly play a role. BC appears to be cost-efficient in spending less on cancer drugs per capita while achieving better outcomes compared to other provinces. The province thus provides a positive example of the integration and equitable distribution of a cancer care program, administered by a single specific body within a regionalized system.

13. This information is available on the Web site of the BC Cancer Agency at www.bccancer.bc.ca.

5.1.3 Alternative outpatient delivery settings

The concept of 'closer to home' chemotherapy, delivered in local treatment clinics or hospitals, was introduced in section 4 on the basis of interviews with rural service providers in Québec and Ontario. The BC Cancer Agency model described above makes full use of this strategy for rural cancer patients. Providing home chemotherapy in remote areas presents logistical, financial, and efficiency difficulties if home visits are necessary and will, in fact, be impossible for those living too far from a local hospital, for reasons of safety. 'Closer to home' cancer patients do not need to be as highly selected as those currently eligible for home care, since they receive treatment in a supervised environment with capacity for immediate emergency response. (It is indeed interesting that home chemotherapy is most suitable for the more ambulatory cancer patients who have greater ability to travel and can visit outpatient clinics relatively easily.)

For oncology patients in rural areas of Québec, it appears more worthwhile to first concentrate effort on the creation of 'closer to home' chemotherapy settings, rather than home treatment. These facilities could be patient-friendly clinics that allow those living out of metropolitan areas to receive care in their region of residence, and offer patients the advantages of reduced travel time and costs. The challenge for these local settings would be to guarantee the same standards of care as in urban outpatient departments, in order to ensure patient confidence and use. This has been addressed in rural Ontario by strong training and communication links between nurses and family physicians in local hospitals and oncology staff at regional cancer centres.

We present two studies on rural cancer clinics in northern Ontario, as they are instructive for the planning of treatment initiatives in remote regions of Québec. Bakker and colleagues carried out a qualitative study on rural patients' perspectives of chemotherapy [Bakker et al., 2001]. Twenty-eight cancer patients who had received chemotherapy in the last 2 months in 13 different rural clinics were recruited through the regional cancer centre (RCC) at which they were

registered. All of the clinics were located more than 100 km away from the RCC. The study participants were 57% female, 89% married, and had a variety of cancers (the most frequent being breast and colon cancer). Age varied from over 30 to over 70 years, with two-thirds of the sample being 51 years or older. Almost half of the respondents had at least some high school education and 29% had been to college or university. Some of the participants had received their first treatment cycle at the RCC. Twenty-six of the patients completed their chemotherapy at the local clinics, while two chose to finish treatment at the RCC after initial therapy closer to home.

Two themes arose from the patient interviews. A 'balancing gains and losses' theme reflected the decision-making process in choosing chemotherapy location: quality of life (related to travel time, disruption of family life and routine, support networks, and relationship with local health care providers) was weighed against perception of biomedical expertise. This expertise related to technical competence, the presence of other cancer patients, access to new technology and information, and availability of oncology specialists. The level of the patient's value of these two dimensions was critical to the decision about where to receive chemotherapy. For most participants, gains in quality of life from 'closer to home' treatment outweighed gains in biomedical expertise offered by the RCC. Appointments at the RCC were perceived as highly stressful due to the travelling and increased burden on the patient and his/her family. For the two participants who chose chemotherapy at the RCC instead, biomedical expertise was more highly valued. Although travelling was difficult, one of these patients expressed an appreciation for the increased sense of security afforded by the experience level of the RCC oncology nurses.

The second theme was related to the importance of 'communication links', both between patients and health care professionals and between health care providers at the local clinic and the RCC. Effective communication links—and signs of these operating between the clinic and cancer centre via telephone, fax, or computer—gave the patients a sense of security and continuity of care. The Québec study of cancer patient needs in 1995 likewise highlighted the importance of receiving clear, comprehensive information from health care providers with good communication skills [Fraser, 1995]. Bakker and colleagues stress the importance of gathering qualitative information on the patient's perception of different cancer care delivery models [Bakker et al., 2001]. They mention their ongoing involvement in a larger evaluation of the community clinic network in terms of impact on patients and providers, which will include a comparison between patients receiving care at the local clinic and regional cancer centre sites.

The community cancer clinic system in a second northern Ontario region was the focus of an evaluation carried out between 1997 and 1999 [Minore et al., 2001]. The evaluation involved two sets of site visits in two representative remote communities, interviews at the regional cancer centre, and a regional survey of patients and care providers. A total of 75 interviews took place and surveys were completed by 65 health care professionals, 48 cancer patients, and 37 family caregivers. The community program was initiated by the cancer centre in 1992 and has extended to 13 satellite clinics in rural towns, located 100-600 km from the RCC. As mentioned in section 4.2, program costs and resources are shared between the RCC (responsible for training, drug costs, quality of care monitoring, enhancing communication links, and professional support) and the local hospitals (responsible for operating costs including personnel time and supplies). Start-up funding was also provided for the purchasing of equipment such as infusion pumps, pharmacy fume hoods, computers, and videoconference facilities.

The community cancer care program was associated with an increase in patient volumes throughout the region. Treatment quality at the local sites was considered high, but several organizational difficulties were identified. These included (1) staffing concerns particularly due to turnover of trained oncology physicians and a shortage of family physicians in the region; (2) problems maintaining continuity of care in the face of increased numbers of patients and/or more complex care regimens (related to staff shortages and treatment times extending past an

8-hour shift); (3) the challenge of maintaining provider competency with part-time staff; (4) prevention of nurse burnout due to work overload (particularly due to managing patient questions and calls outside office hours, and often being the only experienced nurse on duty); and (5) insufficient supportive care services in the communities. Factors which contributed to the success of the program included the support of the patients, the positive attitude of the administrators and care providers involved at the RCC and locally, and the increased expertise and independence of the rural health care professionals.

Some of the issues raised by this evaluation echo a keynote address presented at a National Conference on Community Cancer Programs in Winnipeg, Manitoba in 1990 [Kaluzny, 1991]. Kaluzny presented several guidelines for the development of 'strategic alliances' between different organizations involved in delivering care to rural cancer patients: (1) reaffirm the role of local practitioners as partners in the program; (2) formally define the organizational, procedural, quality control, and communication structures; (3) manage the program in a way that encourages response to the needs of different stakeholders; (4) establish data systems to monitor performance and impact; and (5) be realistic in setting target goals and time commitment.

Turning to the province of Manitoba, a decentralized chemotherapy program known as Outreach has been created to bring treatment closer to home for rural cancer patients [Nemecek and Schipper, 1990]. While less populated than Québec, Manitoba likewise has a concentration of people in the south and a sparse population in vast rural areas. We present the organizational structure of the Manitoba program based on Nemecek and Schipper's report. Family physicians, supervised at a distance by oncologists, manage treatment locally in rural hospitals; each remote site must have at least 25 new patients annually, appropriate laboratory and pharmacy facilities, the ability to monitor quality of care, and two community physicians willing to be responsible for delivering the program. Outreach began at five hospitals (with 100 beds or more) and a controlled study of patients served by the program found them to be similar to patients treated at the urban cancer centre, in terms of amount of chemotherapy received, drug toxicity, and survival rates. The Outreach physicians are considered to be intermediaries between the patient, his/her referring general practitioner, and the urban oncologist who specifies the care plan. The community doctors must be able to recognize 'critical decision points' during the patient's treatment and bring these to the attention of the oncologist.

Manitoba patients are always offered the option of chemotherapy at the urban centre instead. The Outreach program is coordinated and evaluated centrally at the urban cancer centre, where nursing, pharmacy, and treatment protocols are standardized and provider training takes place. The coordination team includes a director, coordinator, pharmacist, data manager, and two systems analysts, with links to records and information services at the urban cancer centre and tertiary care nurses, oncologists, and pharmacists.

Nemecek and Schipper point out that pediatric cancer patients were rarely eligible to be in the Manitoba Outreach program due to their small numbers. A recent qualitative study in the same province examined the experience of having a child with cancer from the perspective of 10 rural families [Scott-Findlay and Chalmers, 2001]. Twenty-five family members participated in semistructured interviews, including 12 children (patients and siblings). The cancer treatment for these patients was provided at a single tertiary centre in the provincial capital, 63-460 km away from their homes. The average number of trips made to the treatment centre was 61 (range: 8-250) and the average distance driven was 14,281 km (range: 3,510-27,000).

Due to the extreme distances from their homes to the urban centre, the rural families experienced major financial hardship, substantial burden and stress, and needed to take greater responsibility for emotional support and medical care of their child. Families described driving long distances with the child feeling ill from chemotherapy, having to arrange care for other children and additional farm help, having fewer formal community resources to assist them, job pressures and decreased work performance,

stressful driving conditions (busy roads, bad weather), frequent disruption of the family unit, and lack of a support network when staying in the city during treatments.

Parents felt they often had more understanding of the cancer treatments than the local health care providers. Some parents gave chemotherapy in the home or drew blood from central lines without the support of local nurses, who were perceived as being afraid of the procedures. For some families, specialized health care professionals in the urban setting were perceived as not appreciative of the additional challenges they faced and not aware of the level of local services available. The study highlighted a need for (1) improved coordination of care and exchange of information between the urban centre and rural settings; (2) ways to decrease costs (e.g. free parking, meal cards, toll-free calls, and programs to provide financial aid); (3) access to counselling services; and (4) an increased role for oncology nurses in assessment of family resources, transfer of skills to rural care providers, and planning of family-centred care.

Outside of Canada, a systematic review of cancer treatment programs in remote and rural areas found 15 evaluations published between 1978 and 1997 in the USA, Australia, and the United Kingdom [Campbell et al., 1999]. Although the general strength of the evidence represented by these studies was rated to be suggestive rather than conclusive, there were indications that shared approaches between rural health care professionals and specialists worked and made specialist care more available through general practitioners. A more recent financial analysis of a rural cancer outreach program in the USA showed increased access to cancer care for rural patients with decreased annual costs per patient and what appeared to be more efficient resource use [Desch et al., 1999]. In this program, specialists from the partnering academic medical centre travel once a week to the two rural sites to develop a care plan for patients diagnosed at the rural hospitals. This care plan is then managed by the local primary care physician. Routine cancer care is received at the rural hospitals, including chemotherapy for all cancers except acute leukemia. An oncology nurse coordinator residing in the rural community and a nurse specialist from the medical centre provide about 75% of the medical care. Patients are transported free by van to the urban centre for radiotherapy (130-145 km away).

5.1.4 Basic requirements for organization of home chemotherapy services

Based on the literature reviewed in sections 3 and 5.1, as well as the section 4 interviews with clinical and administrative staff in Québec and Ontario, we conclude that a number of factors are necessary for effective, efficient, and safe delivery of home chemotherapy. The following list contains both intra- and inter-organizational aspects:

- highly-trained nurses with specialization in oncology and time availability for structured education of patients/informal caregivers and training of home visiting nurses;
- full participation of oncology pharmacists;
- support of autonomous decision-making by oncology nurses and pharmacists;
- highly-effective 'one-on-one' patient and caregiver training;
- efficient coordination of the home chemotherapy program, from patient selection and training to discharge and management of home care services;
- well-defined program protocols (e.g. regarding patient selection criteria, treatment delays), chemotherapy treatment protocols, and safety policies (e.g. for drug preparation, delivery, administration, and disposal, and emergency procedures);
- efficient transfer of complete patient information within the health care team and between organizations;
- excellent communication links between team members and organizations;
- clear delineation of professional roles and responsibilities for all formal care providers;

- continuous and easy patient access to medical staff while at home (e.g. 24 hours/day, 7 days/week telephone access);
- committed physician back-up and support;
- timely laboratory support (e.g. blood test results within 48 hours of drug administration);
- well-trained, self-sufficient home visiting nurses (e.g. CLSC nurses);
- appropriate team size for patient load and continuity of care;
- realistic budget at all sites involved in the program to ensure sufficient resources;
- effective alternatives for ineligible patients, such as 'closer to home' chemotherapy clinics in rural areas.

Sources: DeMuro, 1980; Garvey, 1987; Esparza et al., 1989; Ophof et al., 1989; Javahone et al., 1992; Parker, 1992; Kane, 1995; Lowdermilk, 1995; Cozzi, 1996; Gorski and Gustheman, 1996; Holdsworth et al., 1997; Dougherty et al., 1998; Serrate et al., 2001; Regroupement des pharmaciens en oncologie, 2001.

The above factors have important implications for professional training, team coordination, organizational infrastructure, human resources management, and budget and financial management at all sites involved. They display the varied role implications for a multi-disciplinary team that includes nurses, physicians, pharmacists, visiting nurses, laboratory technicians, and other service providers (e.g. delivery personnel).

Of utmost importance is the ability of the service team to respond to the cancer patient's needs. As mentioned previously, the *Comité consultatif sur le cancer* carried out a qualitative study on the needs of Québec patients and their caregivers in the mid-1990s [Fraser, 1995]. The principal needs identified by patients included (1) humanization of contacts with health care professionals during diagnosis, treatment, and follow-up; (2) use of simple, understandable language by medical personnel; (3) patient participation in decision-making and control of their therapeutic choices; (4) psychosocial information and support immediately following diagnosis; (5) comprehensive information on public, community, and private resources available to them; and (6) being in contact with a key person on the oncology team who is responsible for their follow-up and who can answer their questions. Respondents pointed to 'gaps' in the support services available in the community to respond to physical, financial, material, and practical needs of patients, despite the presence of CLSCs and voluntary organizations; these gaps often had to be filled by help from family members or friends (e.g. with transport, domestic help). This incompleteness of support decreased the quality of life of the patient and their caregivers and had an effect on the possibility of receiving appropriate care and treatment at home.

The *Comité consultatif sur le cancer* also identified a number of 'gaps' in the organization of cancer services in Québec based on its consultations [Fraser, 1995]. These included (1) an absence of systematic organization of health care services; (2) inefficient mechanisms of patient follow-up, due to lack of communication between service providers, non-systematic transmission of information, lack of a formal referral process between professionals, and difficulties of access to certain services; and (3) non-uniform accessibility to services across the province.

5.2 ETHICAL AND LEGAL ISSUES

5.2.1 Ethical and legal issues to be faced by service providers and institutions

Home chemotherapy presents legal and ethical challenges related to the home setting (where a nurse may visit alone, and/or the patient under treatment may be unsupervised for long periods of time), the potential for uncomfortable side effects and even life-threatening events due to the toxicity of the chemotherapy drugs, and the specific context of being diagnosed with cancer. Health care that is ethical respects the principles of autonomy, beneficence, non-maleficence, and justice [Latimer, 1992]. Some of the relevant legal issues in health care overlap with ethical aspects since laws provide a framework to enforce accountability and good professional practice. In the sections below we focus on ethical issues, but also comment briefly on legal practices where relevant. Legal issues surrounding the use of high-tech equipment in the home was discussed in

length in a separate AETMIS report [Lehoux and Law, in press].

5.2.1.1 ETHICAL PRACTICE AND PROCEDURES

In terms of professional conduct, several steps must be followed in order to deliver quality and ethical cancer care and chemotherapy at home. The oncologist must present clear and comprehensive information about the cancer diagnosis and possible courses of treatment [Latimer, 1992], and must respect the patient's right to decide about treatments according to his/her personal values (autonomy). Throughout the course of the cancer illness, the patient may need to make a number of different and difficult decisions about his/her care depending on the outcome of treatments. The seriousness of the cancer diagnosis means that patients can be very frightened and upset when making these choices. At each decision-making stage, the potential benefits of chemotherapy (which are often expressed as probabilities) must be weighed against the burden presented by possible (or even likely) side effects. In oncology the beneficence of chemotherapy, then, is represented by the trade-off between these two possible treatment outcomes. The physician also needs to recognize when continuing cure-oriented and aggressive therapies becomes 'over-treatment' (thus respecting non-maleficence). Choices made by cancer patients can indeed be a matter of 'life or death', and health care professionals working in cancer care need to achieve a certain level of acceptance of the fact that many of their patients die [Latimer, 1992].

The patient with cancer must be fully informed about the implications of chemotherapy protocols in general and receiving therapy at home in particular [Kane, 1995; Latimer, 1992; Garvey, 1987]. If informed consent to receive cancer chemotherapy in the home is obtained, this must be documented [Parker, 1992]. This process both demonstrates ethical practice and serves a legal function. In respecting the patient's autonomy, there needs to be recognition of the possibility that a patient may refuse treatment once a visiting nurse arrives at the home [Lowdermilk, 1995]. The person(s) ultimately responsible for the patient's care at home must be clearly identified at the outset of treatment (this will be discussed further in section 5.2.1.4) [Parker, 1992]. The health care professionals involved in the multidisciplinary home chemotherapy team must follow policies that reflect best practices. Such policies should be comprehensive while allowing for clinical judgement to be applied [Scales, 1996]. In the face of emergencies with toxicity or technical problems, appropriate action must be taken in accordance with set protocols; most often, it will be the nurse who must respond to this situation on his/her own.

Adherence with best practices requires appropriate training in both the hospital and community environments. The movement of nursing practice from a supervised environment to the home requires independence and decision-making autonomy, aspects which may be more familiar to community nurses who have experience in home care. At the same time, however, the involvement of visiting community nurses in chemotherapy requires the transfer of specialized knowledge from oncology nurses. Cancer care can be perceived as frightening by nurses unfamiliar with the domain. Quality assurance mechanisms are required to ensure an acceptable standard of care from all professional services involved in home chemotherapy (i.e. nursing, oncology medicine, home care nursing, pharmacy, laboratory, equipment manufacture and supply) [Parker, 1992]. Clear and concise documentation of services delivered is important for quality control. Patients' records should be accurate and timely, contain complete and factual information, and demonstrate adherence with the care plan (or clearly specify reasons for not being able to adhere) [Bowers and Adams, 1999].

We close this part with a few comments about the patient's right to care of the highest quality. We found it surprising that many home chemotherapy programs we heard about in our interviews did not automatically involve a visit to the patient's home (due to limited resources). This raises a question: How can hospital nurses—who are usually charged with the patient assessment responsibility—be sure about the patient's home environment and its suitability for chemotherapy if nobody visits the home? Secondly, ethical health care involves responding

to the patient's needs appropriately and effectively and assisting the patient as a whole person [Latimer, 1992]. A truly comprehensive cancer care system is one that provides supportive services (e.g. access to counselling and home help) and commits the necessary human and financial resources to ensure a continuum of care from the hospital to the community setting.

5.2.1.2 PATIENT ELIGIBILITY AND EQUITY OF ACCESS

Health care that upholds the principle of justice implies fair distribution of goods and services [Latimer, 1992]. There are highly restrictive eligibility criteria for home chemotherapy, in order to minimize risks to safety. For some cancer patients, there will be no choice but to receive treatment in an institutional setting. This aspect of home chemotherapy must be recognized: if the prescribed treatment protocol can be delivered in the home, the choice of treatment setting can be offered only to patients with particular characteristics (related to, for example, geographic location of residence, home suitability, and perhaps availability of a motivated caregiver who can be trained in technical skills). At a few sites we spoke to in Ontario, certain continuous infusion therapies were only offered at home: if the home option was not accepted an alternative non-continuous treatment regimen was devised so that chemotherapy could be delivered in an outpatient setting. The reality is that patients in urban settings have more access to chemotherapy at home. For patients in rural areas, the 'closer to home' chemotherapy model provides them with more choices and helps lessen their travel burden, as described in section 5.1.3.

One of the contacts we interviewed pointed out that the regional cancer centre system in Ontario helps ensure all hospitals in the province have access to the same chemotherapy drugs and treatments. The British Columbia Cancer Agency model likewise ensures equal access in that province. A more individualized approach at Québec health care institutions, without some kind of management at a regional or provincial level, may lead to patients 'shopping' for the best options offered by different programs.

5.2.1.3 PATIENT CHOICE WITHIN THE HEALTH CARE SYSTEM AND ALLOCATION OF RESOURCES

A recent randomized controlled trial of a home chemotherapy program in Australia (which found it to be associated with higher marginal costs) prompts the following question: From the health care system perspective, what happens if some patients prefer home chemotherapy, but it is actually more expensive [King et al., 2000]?

It is clear that, as pointed out by Lowenthal and colleagues, "home chemotherapy services offer an alternative to—not a replacement for—day clinics, which provide treatment for a broader range of patients" [Lowenthal et al., 1997, p.110]. In many circumstances cost implications are not clear: when the alternative to home care is outpatient treatment, for example, or when a large financial investment is required to build infrastructure and buy equipment for home care. In the end, shouldn't the decision to make home chemotherapy available rest on "humanitarian and clinical grounds" rather than on concerns about short-term cost savings to the health care system [Jennings, 1994, p. 905 quoting Marks, 1990]?

5.2.1.4 LEGAL ACCOUNTABILITY

A comprehensive home chemotherapy program is one which involves the services of a number of different professionals, including hospital and visiting nurses, oncologists and general practitioners, pharmacists, hospital and CLSC administrators, laboratories, and equipment manufacturers. The respective roles of each of these players must be clearly specified, in order to determine responsibility if something goes wrong. For example, problems can occur as the result of a technical error made by a nurse (either in the home or in the hospital as part of an emergency response, or even made remotely through telephone contact with the patient), by a pharmacist dispensing the chemotherapy drug(s), or as a result of equipment malfunction. It can also be the patient or informal caregiver who makes an error of judgement or technical handling in the home.

In addition to the clear delineation of professional responsibilities, the risk of legal liability can be decreased by adhering to the highest quality care protocols and safety policies and ensuring optimal training and qualifications of all care providers involved [Kane, 1995; Parker, 1992; Garvey, 1987]. The paths of communication in the case of an emergency must be clear to the patient (e.g. who is called where, at what time of the day, and for what kind of problem), and the home patient must be fully aware of the possibility of needing immediate hospital emergency support [Garvey, 1987]. Documentation of problems and actions taken must be comprehensive. It is also important for the nurse and/or pharmacist responsible for patient assessment and training to document and bring to the attention of the treating physician any factor which would make a patient unsuitable for home therapy (e.g. high levels of anxiety, inability to follow instructions, or incompatible home environment) [Parker, 1992; Garvey, 1987].

5.2.2 Ethical and legal issues to be faced by the patient and caregiver(s) in the home

The most important aspect of home chemotherapy delivery, when applicable and available, is acceptance of the treatment by the patient. It should be recalled that home chemotherapy, as defined in this report, includes administration of cytotoxic treatment without on-site supervision by a health professional. Although most of the programs we heard about in our interviews did not require an informal caregiver (family member, friend, neighbour, or volunteer) to be present during therapy, a support person is strongly advisable. Even if chemotherapy is delivered in the outpatient setting, the effects of the illness and side effects from treatment will be experienced by the patient at home and he/she usually needs help from household members. For example, a telephone survey of 597 American patients (aged 21-81 and 71% female) who had received cancer chemotherapy at hospital and private outpatient clinics within one month of interview found that 90% needed help with a 'personal, instrumental, or administrative' activity [Guadagnoli and Mor, 1991]. These activities included housekeeping, transportation, meal preparation, completing forms, bathing, and home health care. Greater levels of need were reported by patients with children at home. Sixty-three percent of respondents in this study were receiving 'palliative' chemotherapy.

Providing care to a family member with cancer represents an emotional, psychological, and physical challenge. A study by Schumacher and collaborators addressed issues faced by informal caregivers assisting chemotherapy patients [Schumacher et al., 2000]. Qualitative interviews with 30 cancer patients and 29 of their primary family caregivers (done at different times during the first chemotherapy experience) were used to examine the concept of "family caregiving skill". Nine dimensions of the caregiving role were identified: monitoring, interpreting, decision-making, taking action, making adjustments, providing hands-on care, accessing resources, working together with the ill person, and negotiating the health care system. Caregiving skill was perceived as a blend of previously and newly developed skills, which involved integrating knowledge of personal aspects of the patient with knowledge of cancer care, and developed with time and experience.

Adding to this complexity is the reality that some caregivers will be 'better at it' than others, many can feel under pressure to provide help to the patient, and some will take on too much. A responsive home chemotherapy program is one that allows for patients and their caregivers to decide the burden of care is too great and return treatment to the hospital setting. Careful assessment of the patient and caregiver's progress during training for home treatment can help identify problematic situations, although health care professionals also need to be sensitive to the unique relationship they are witnessing from the outside [Schumacher et al., 2000]. The perspectives of both the trainer and the trainee(s) are important to help the patient (and caregiver) make the final decision about home care.

Assistance with the administration of chemotherapy and management of venous access lines and infusion pumps requires both patients and their caregivers (including parents of pediatric

patients) to gain highly technical knowledge and skills. Caregivers need to feel comfortable with the delegation of nursing tasks to them. A Canadian study is particularly helpful for a discussion of caregiver burden, although improvements in equipment are likely since its publication year [Bubela, 1981]. Bubela examined the perspectives of four cancer patients and their spouses on the experience of intra-arterial chemotherapy infusion using a catheter and pump. In a period of 4 months, these patients were seen weekly in the outpatient department and therapy was continuously infused for 4-6 weeks. Because patients had one arm immobilized in a sling, it was crucial that their spouses manage the treatment. The study participants were interviewed several times and all were in their 50s and 60s. Spouses were taught to fill and change syringes and recognize and monitor side effects and complications.

All couples reported having difficulty with the technical aspects of care (blood or air in tubing, disconnection of tubing from the pump, problems drawing up heparin and medication), and side effects (nausea, weight loss, fatigue) were present throughout treatment. Two couples experienced crises within a few days of discharge (cracked tubing and backing up of blood) which led them to check the lines periodically throughout the night for the remainder of the treatment duration. Nursing visits to the home to change dressings were not consistent in terms of who came and when; sometimes the spouse had to change the dressing (without having been trained) because the visiting nurse did not come. All of the spouses were nervous about their care responsibilities and upset and/or afraid when technical problems occurred. Two couples felt they had not received enough information about the infusion therapy. The patient's loss of weight and appetite was also stressful for the spouses to witness. At the same time, patients had periods of depression, irritability, and non-communication. As time passed, concerns about technical problems lessened and those related to the patient's state and behaviour intensified. The patients needed to be bathed and helped in getting dressed; three of four spouses remained home during the treatment.

The informal caregiver's role is thus complex and important when cancer patients receive infusions of chemotherapy at home. In the context of a comprehensive cancer care system, one could pose the question: Should family members and other non-professional caregivers managing intravenous chemotherapy be compensated financially for their contribution to cancer care? [Hébert et al., 1997; Kane, 1995]. The recent Romanow Commission final report on health care in Canada has recommended the development of proposals "to provide direct support to informal caregivers to allow them to spend time away from work to provide necessary home care assistance at critical times" [Romanow, 2002, p. 252, recommendation 35].

Proper attention to and management of the ethical and legal issues raised in section 5.2 are crucial for the set-up, coordination, and delivery of high quality home chemotherapy. These issues should be kept in mind in order to frame the conclusions made in the final section of this report.

6 SUMMARY AND CONCLUDING REMARKS

6.1 CONCLUSIONS

Our review of the evidence in the scientific literature concerning home chemotherapy for cancer was enriched with semi-structured interviews with service providers in Québec and Ontario. There is insufficient evidence on the clinical effectiveness of home chemotherapy compared to non-home settings. There is more evidence to show that home treatment can be delivered safely, with few serious complications or accidents, although patients must be carefully selected and trained. Where home chemotherapy replaces inpatient treatment, convincing evidence of cost savings for hospitals and families arises from only one pediatric study. In studies where home chemotherapy replaces outpatient treatment, the mixed findings and variable study quality prevent a conclusion on the cost implications. Home chemotherapy causes cost shifting within the health care system from hospitals to home care organizations. Effects on costs to Québec hospitals and home care services, and to cancer patients and their families/informal caregivers, require more study. Improvements in patient quality of life at home have not been well documented in the literature, but are consistently reported anecdotally by care providers. Patient preference for and satisfaction with home therapy is supported, although the published evidence in this regard mostly arises from studies where acceptance of the approach is required to participate.

Interviews with clinical and administrative personnel in Québec and Ontario showed variable delivery of home chemotherapy, with greater uniformity of services and more structured programs where inter-organizational collaboration was supported. Interviews with rural providers pointed to a need for alternative outpatient delivery 'closer to home' in remote areas. Establishing safe chemotherapy practices at home is resource intensive and requires a well-integrated, collaborative team of health care professionals. Chemotherapy delivery in any setting requires specially trained personnel. The home delivery model cannot wholly replace outpatient treatment, especially in the rural setting, but can be a safe and acceptable option for some cancer patients who choose it, particularly those receiving simple continuous infusion treatment.

Certain conditions must be in place in order to ensure high quality chemotherapy in the home setting; these aspects should be taken into account when such initiatives are implemented. We make several recommendations about these conditions in section 6.3. This assessment has led us to an additional recommendation related to access to chemotherapy: for rural cancer patients in Québec, priority needs to be given to the establishment of 'closer to home' chemotherapy.

6.2 LIMITATIONS OF THE REPORT

Several limitations apply to this report. The lack of province-wide information on the relative use of inpatient, outpatient, and home chemotherapy, as well as feasibility issues, precluded us from being able to collect comprehensive data on current modes of chemotherapy delivery from across Québec. Instead, we looked at programs in a limited number of areas in order to gain general perspectives on the major issues in home chemotherapy from the healthcare provider's point of view. Secondly, the scientific literature and our qualitative interviews revealed a lack of cost data from Québec and Canada, both from the perspective of the health care system and the patient. The published cost data are not easily applicable to the Canadian health care system. A randomized study in the pediatric cancer setting, underway in Ontario at the time of interview for this report, will likely prove to be informative in this regard.

Appropriate level of use of home chemotherapy depends somewhat on which inpatient and outpatient treatments it can replace (when a prescribed protocol can actually be delivered at home). This will likely modify in the future depending on the relative use of continuous intravenous infusions versus oral therapies. Oral

drugs, while still requiring some level of supervision and/or education to ensure treatment compliance and correct dosing due to their toxicity, clearly do not require the same technical expertise nor as great an investment in human resources and equipment for their delivery in the home.

Finally, there are insufficient data on the Québec cancer patient's points of view on the delivery of chemotherapy in different settings, and on the experience of home chemotherapy in particular. Although home chemotherapy is being provided in Québec using several different types of treatment modalities, systematic evaluation of programs in terms of patient preferences and satisfaction appears to be missing. We recognize the need for such data to be generated. A comparative study of home versus inpatient versus outpatient chemotherapy, from the perspective of urban and rural cancer patients in Québec, is a possible approach. In this context, the use of both quantitative and qualitative validated tools would be recommended.

6.3 RECOMMENDATIONS

We have grouped our recommendations for Québec policy-makers, health care administrators, and care providers according to a number of issues.

(1) Support for program evaluation
In light of the insufficient evidence, there is a need for well-designed evaluations of home chemotherapy before its use is greatly expanded in Québec. In our interviews, we noted a lack of funds and time availability to carry out assessments, although one Québec site we visited had received a clinical innovation prize for their program initiative, for which an evaluation report had been completed. Comprehensive and ongoing evaluation of home chemotherapy programs is a crucial aspect of quality control. Program developers should be rewarded for their initiative and achievement of certain standards of care. Eligibility for specific home chemotherapy funding from regional agencies could be linked to program evaluations that show appropriate positive outcomes. Program assessments must include the patient's perspectives on quality of life and satisfaction; patients and their informal caregivers take on many care responsibilities during chemotherapy at home. Economic evaluations of programs should be carried out from a societal perspective, including costs of drugs, medical supplies and equipment, personnel (including time spent on patient teaching and follow-up, telephone contact with patients, and home visits), hospital service use (at outpatient clinics, emergency rooms, and inpatient departments), community health service use (at CLSC clinics), drug storage and delivery, teaching manual and program development, other supportive care use (e.g. domestic help, counselling), and expenses saved/lost by the patient and his/her family and caregivers (e.g. travel, child care, employment income) [Thickson, 1993].

We view the evaluation of existing home chemotherapy programs in Québec as a priority in the light of insufficient data on effectiveness, costs, and the patient's perspective. In the meantime, the following issues should be considered by both program evaluators and current providers.

(2) Standardization of general policies and program components
Considering the current provision of home chemotherapy in Québec, we observed a need for basic provincial policies that set safety and program standards and provide structure for chemotherapy services both at home and in the rural hospital clinic environment. Several of our contacts stressed the importance of current initiatives to standardize treatment protocols in the province. This standardization could be extended to centralized policies specifying the basic components of home chemotherapy programs and 'closer to home' services (with respect to organizational structure, staffing requirements, professional training needs, communication links, emergency support for patients, and patient follow-up, for example). Initiatives such as the extensive chemotherapy guide developed by the *Regroupement des pharmaciens en oncologie* should be supported and widely diffused, and are an important step towards standardization of policies. In Ontario, greater uniformity of services and capacity to respond to both urban and rural patients' treatment needs appeared to be assisted by a regionalized approach with centralized

funding, inter-organizational collaboration, and a certification system for rural clinics using standardized protocols.

(3) Enhanced collaboration and communication
The formation of multidisciplinary teams working together to provide the best care to the patient undergoing home or 'closer to home' chemotherapy is essential. This can be facilitated through such initiatives as standardized, accessible patient information sheets, the designation of a key health professional to coordinate care for the cancer patient, and training programs (e.g. oncology nurse—CLSC nurse teaching; teleconferencing and other remote communications for rural health professionals, site visits, annual conferences). At some sites it could be useful to form a coordination team to liaise between the different organizations involved (e.g. hospitals and CLSCs). In the absence of home visits by oncology nurses, there is a possibility for an increased role for CLSC nurses in the support of home chemotherapy.

(4) Central standard setting but a regionalized approach
At the same time as detecting a need for standardized policies to ensure quality of care in home chemotherapy programs, we recognized the diversity of initiatives at different institutions and in different regions (e.g. rural versus urban). Central surveillance of programs, as a component of cancer treatment services, could be managed by a body such as the MSSS or DLCC. Roles for such an organization could include setting basic standards and general objectives. However, the specific planning and budgeting for programs should likely fall under the domain of the *agences régionales*, who are better able to respond to the needs of their specific areas. A strategy could be developed whereby multidisciplinary hospital teams are encouraged to submit proposals to the *agences* regarding a home chemotherapy or 'closer to home' treatment service, in order to receive funding for program delivery and evaluation. In this way, regional bodies would be able to ensure high quality services while allowing for flexibility since different institutions (e.g. hospitals, CLSCs) may differ in their enthusiasm to be involved in these program initiatives. For example, depending on the site, oncology nurses could be involved in making home visits, or CLSC nurses could have more involvement in cancer care and be able to obtain specialized training. A regionalized approach is, in fact, favoured by the *Programme de lutte contre le cancer* (as we saw in section 1.1.1 [MSSS, 1997b]), and the DLCC initiatives.

(5) Increase in resources and use of specific budgets
The home chemotherapy programs we examined in Québec were restricted by a lack of financial and human resources (nurses, pharmacists), despite there being a general consensus that demand for services at home would increase. We were surprised to find that a home nursing visit was not specifically required by any of the Québec home programs we studied. In comparison, at three of the four urban Ontario sites we examined, home visits during treatment (but not continuous on-site supervision) were an integral part of the service. Depending on the results of program evaluation proposed above, increased resources will likely be needed by current home chemotherapy programs in Québec, and particularly if services are expanded, to guarantee a high quality of care. The financial support of the transfer of skills from oncology to community nursing appears to be particularly lacking. Sharing of expertise between nursing domains (e.g. oncology nurse—community nurse) and between physician domains (e.g. oncologist—general practitioner) is crucial for high quality cancer care and continuity of care in the province. The use of specific budgets for home chemotherapy relieves the burden of having to 'borrow' nursing time from inpatient and outpatient departments. Although only a minority of chemotherapy patients are able to have treatment at home at present, the technological and safety aspects are such that an integrated approach involving a number of different health care professionals must be sufficiently resourced. The value of supportive care services in the community—for cancer patients receiving chemotherapy both at outpatient clinics and at home—cannot be underestimated.

(6) A comprehensive model of provincial cancer care

Finally, in carrying out this assessment it became apparent that issues regarding chemotherapy access and giving cancer patients the choice of quality treatment in the home environment are fundamentally related to the overall vision of and policies for cancer care in the province. A home chemotherapy program, in fact, presents a 'microcosm' of the general issues in cancer care: the need for comprehensive services that address different patient needs at different stages of their illness/treatment process and the integration of many disciplines and services to promote wellness. The objectives delineated by the *Programme de lutte contre le cancer* and the DLCC's initiatives in cancer care organization represent an important starting point for the development of a comprehensive framework that addresses the varied and changing needs of cancer patients in Québec [MSSS, 1997b].

APPENDIX

QUESTIONNAIRE USED FOR INTERVIEWS WITH CLINICAL TEAMS AND ADMINISTRATORS

(English version)

ORGANIZATION OF SERVICES

Description of home chemotherapy service: What is provided? Since when?

Team members: Who are they; how many are involved?

Patient referral process: How is this done?

Equipment (access devices, pumps, catheters, drugs): Who supplies them; who pays for them?

Professional training: What is required; how is it regulated?

Community services: Do they have any involvement in service delivery/management? e.g. CLSC

Professional organizations: Do they have any involvement?

Other questions:

What is the budget?

Is there an annual report?

Does the service have any research components?

PATIENTS

Patient selection: who is eligible (i.e. what criteria are used)? Is a decision tree or protocol used?

Size of patient population: What percentage of those who need chemotherapy are eligible?

Extent of service use: How many patients receive chemotherapy at home per month or per year?

Characteristics of users: What are these? e.g. cancers treated, age, gender, therapy duration

Alternatives: What do ineligible patients receive? Where is their treatment delivered?

Waiting lists: Are these used?

Patient organizations/support groups: Are these involved in any way?

Patient's role in treatment delivery/management: What is their involvement, how are they trained?

Informal caregivers: What is their involvement; how are they trained?

OUTCOMES

Patient benefits: What clinical outcomes are used?

Patient preference/satisfaction: How do they feel about the service? Is this formally measured?

Patient quality of life: Is it favourably affected by the service? Is this formally measured?

QUALITY OF CARE

Guidelines for standards of care: What are used?

Audit: How is this done and how often?

Reporting requirements: What are they, with respect to activity, quality, and intended audience?

SAFETY

Safety and waste management: What are the issues and how are they handled? (e.g. drug delivery and storage; handling accidents and waste)

Liability issues: How are these managed? Who takes responsibility for the patient's care?

COSTS

Price of equipment (access devices, pumps, catheters, drugs): What are the costs?

Payment of costs: What is paid by the institution; what is paid by patients and/or insurers?

TECHNOLOGY

Delivery systems: Which are used?

Ownership: Who owns the equipment? Is there technical support for maintenance/problems?

New/emerging trends: Are new devices/delivery systems being developed/used?

KEY ISSUES IN HOME CHEMOTHERAPY FOR CANCER

What are the key issues (e.g. barriers, challenges, ethical issues, motivating and facilitating factors) from a clinical and organizational perspective?

What aspects of this service could be improved?

What are the key issues from the patient's perspective?

Do you think the demand for this service will increase, decrease, or stay the same?

Do you think there are any alternative delivery systems for those ineligible for this service?

(French version)

ORGANISATION DES SERVICES

Description du service de chimiothérapie à domicile : Quels sont les services offerts ? Depuis quand ? Comment sont-ils organisés ?

Équipe soignante : composition, nombre

Processus d'orientation des patients

Matériel (dispositifs d'accès, pompes, cathéters, médicaments) : Qui le fournit ? Qui le paie ?

Formation du personnel soignant : formatio· requise; réglementation

Liens avec les services communautaires et les CLSC

Rôle des associations professionnelles

Autres :

Budget

Y a-t-il un rapport annuel ?

Y a-t-il des projets de recherche autour du programme ?

PATIENTS

Critères de sélection des patients : critères d'admissibilité; utilisation d'un arbre décisionnel ou d'un protocole

Nombre de patients : Quel pourcentage est admissible à la chimiothérapie à domicile ?

Utilisation des services : Nombre de patients par mois ou par année

Caractéristiques cliniques des patients : Type de cancer, âge, sexe, durée du traitement, etc.

Solutions de rechange : Lieu de traitement, etc., pour ceux qui ne sont pas admissibles

Liste d'attente

Rôle des associations de patients et des groupes de soutien

Rôle des patients et des aidants naturels dans le traitement : Quel enseignement reçoivent-ils ?

RÉSULTATS

Bénéfices pour les patients : Comment sont-ils évalués ?

Préférences et satisfaction des patients : Que pensent-ils des services ? Ces facteurs font-ils l'objet d'une évaluation structurée ?

Qualité de vie des patients : Est-elle meilleure ? Fait-elle l'objet d'une évaluation structurée ?

QUALITÉ DES SOINS

Lignes directrices et protocoles de soins utilisés

Audit de la qualité : mécanisme, fréquence, portée

Quels types d'informations sont consignés sur une base régulière ? À qui servent ces informations ?

SÉCURITÉ ET RISQUES

Quels sont les risques ? Comment sont-ils gérés ? (délivrance des médicaments, récupération des produits souillés, accidents, etc.)

Qui est responsable ? (soins aux patients, accidents, bris de matériel, etc.)

COÛTS

Prix du matériel (dispositifs d'accès, pompes, cathéters, médicaments)

Politiques de remboursement : Que paie l'établissement ? le patient ? l'assurance ?

TECHNOLOGIE

Systèmes d'administration utilisés

Qui est propriétaire du matériel ? Qui est responsable de l'entretien et de la résolution des problèmes techniques ?

Technologies nouvelles utilisées ou en voie d'émergence

ENJEUX PRINCIPAUX

Quels sont les principaux enjeux cliniques et organisationnels ? (obstacles, défis à relever, aspects éthiques, facteurs de motivation, facteurs facilitants)

Quels aspects du service pourraient être améliorés ?

Quels sont les principaux enjeux du point de vue des patients ?

La demande pour ces services va-t-elle s'accroître, diminuer, rester stable ?

Quelles sont les solutions de rechange pour les patients qui ne sont pas admissibles ?

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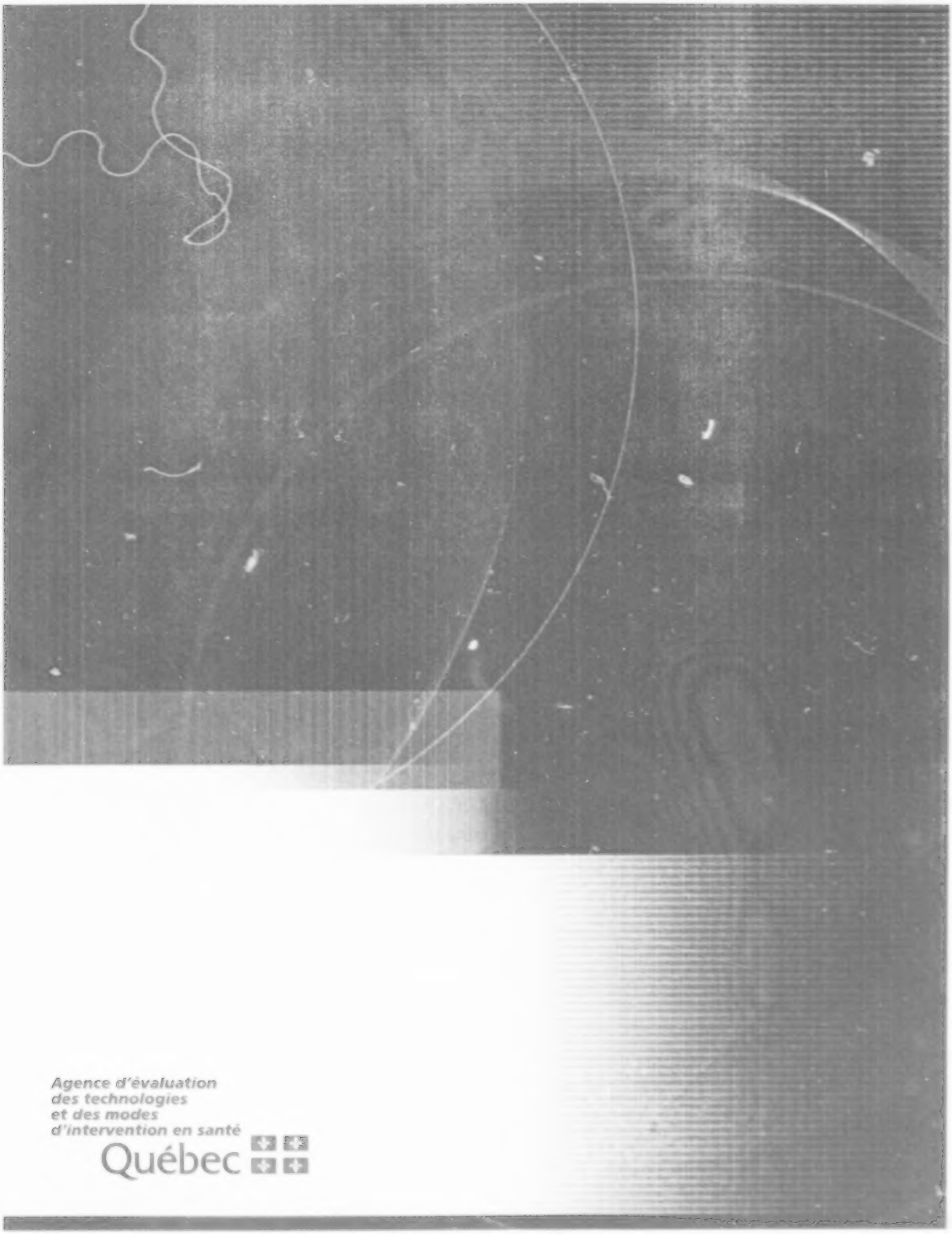

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